CLINICAL PRACTICE GUIDELINE

REPORT OF THE RECOMMENDATIONS

DOWN SYNDROME

ASSESSMENT AND INTERVENTION FOR YOUNG CHILDREN (AGE 0-3 YEARS)

SPONSORED BY
NEW YORK STATE DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH
BUREAU OF EARLY INTERVENTION

This guideline was developed by an independent panel of professionals and parents sponsored by the New York State Department of Health, Bureau of Early Intervention. The recommendations presented in this document have been developed by the panel, and do not necessarily represent the position of the Department of Health.

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2. *Clinical Practice Guideline: Report of the Recommendations.*
   Down Syndrome, Assessment and Intervention for Young Children (Age 0-3 Years). 5½" x 8½", 292 pages. Publication No. 4958.

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   Down Syndrome, Assessment and Intervention for Young Children (Age 0-3 Years). 5½" x 8½", 176 pages. Publication No. 4957.

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Down Syndrome

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Foreword

Providing an optimal early intervention program for young children with developmental disabilities and their families requires knowledge of the most current information on research and practice. However, analyzing research studies and determining their relevance to practice can be a perplexing task even for the professional. Differing methodological and conceptual frameworks often make it difficult to judge the quality of the research and to discern outcome patterns that can and should influence practice.

Despite the fact that this is a difficult task, practice guidelines based on a sophisticated and rigorous analysis of the extant research literature can convey essential information for the design and implementation of optimal early intervention programs. The *Clinical Practice Guideline for Down Syndrome* has been the result of just such a sophisticated and methodologically sound approach to accurately gather and summarize information based on the available evidence.

This document is especially innovative in that it thoughtfully integrates developmental profile studies and research from intervention science to yield the best practice recommendations possible.

MICHAEL J. GURALNICK, Ph.D.
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PREFACE

WHY THE BUREAU OF EARLY INTERVENTION IS DEVELOPING GUIDELINES

In 1996, a multiyear effort was initiated by the New York State Department of Health (NYSDOH) to develop clinical practice guidelines to support the efforts of the statewide Early Intervention Program. As lead agency for the Early Intervention Program in New York State, the NYSDOH is committed to ensuring that the Early Intervention Program provides consistent, high-quality, cost-effective, and appropriate services that result in measurable outcomes for eligible children and their families.

This guideline is a tool to help assure that infants and young children with disabilities receive early intervention services consistent with their individual needs, resources, priorities, and the concerns of their families.

The guideline is intended to help families, service providers, and public officials by offering recommendations based on scientific evidence and expert clinical opinion on effective practices for the following:

- Early identification of children at risk or suspected of having a disability through routine developmental surveillance and screening targeted to identify specific disabilities.
- Provision of multidisciplinary evaluations and assessments that result in reliable information about a child's developmental strengths and needs and, when possible, a diagnosis.
- The determination of effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will lead to positive outcomes for children and families.
- The measurement of outcomes achieved.

The impact of clinical practice guidelines for the Early Intervention Program will depend on their credibility with families, service providers, and public officials. To ensure a credible product, an evidence-based, multidisciplinary consensus panel approach was used. The methodology for these guidelines was established by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care Policy and Research (AHCPR). This methodology was selected because it is a well-tested, effective, and scientific approach to guideline development.

The NYSDOH has worked closely with the state Early Intervention Coordinating Council throughout the guideline development process. A state-level steering committee was also established to advise the department on this initiative. A national advisory group of experts in early intervention has been available to the department to review and to provide feedback on the methodology and the guideline. Their efforts have been crucial to the successful development of this guideline.

Overview of the Early Intervention Program

The New York State Early Intervention Program is part of the national Early Intervention Program for infants and toddlers with disabilities and their families, first created by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA). IDEA is also the federal law that ensures all children and youth ages 3 to 21 years with disabilities the right to a free, appropriate education. In New York State, the Early Intervention Program is established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.

To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the state, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and adaptive development.

The Early Intervention Program offers a variety of therapeutic and support services to infants and toddlers with disabilities and their families, including family education and counseling, home visits, and parent support groups; special instruction; speech pathology and audiology; occupational therapy; physical therapy; psychological services; service coordination; nursing services; nutrition services; social work services; vision services; and assistive technology devices and services.

Major provisions of the New York State Public Health Law that govern the Early Intervention Program require:

- Local administration of the program by an Early Intervention Official (EIO) designated by the chief elected official of each of the fifty-seven counties and New York City. The EIO is responsible for ensuring eligible children and families receive the services included in the Individualized Family Service Plan (IFSP) that is developed for the child and family.
- Identification and referral of children at risk or suspected of disability by primary referral sources (including physicians and other health-care providers).

- Periodic developmental screening and tracking of at-risk children.
- Provision of service coordination services to eligible children and their families.
- A multidisciplinary evaluation of children referred to the program, at no cost to families, to determine eligibility.
- Individualized Family Service Plans (IFSP) for eligible children and their families.
- Provision of early intervention services as specified in the IFSP at no cost to the family.
- Delivery of services in natural settings in the community where peers are typically found to the maximum extent appropriate.

The mission of the Early Intervention Program is to identify and evaluate, as early as possible, those infants and toddlers whose healthy development is compromised and provide for appropriate intervention to improve child and family development. The program goals are to:

- Support parents in meeting their responsibilities to nurture and to enhance their children's development.
- Create opportunities for full participation of children with disabilities and their families in their communities by ensuring services are delivered in natural environments to the maximum extent appropriate.
- Ensure early intervention services are coordinated with the full array of early childhood health and mental health, educational, social, and other community-based services needed by and provided to children and their families.
- Enhance child development and functional outcomes and improve family life through delivery of effective, outcome-based, high-quality early intervention services.
- Ensure early intervention services complement the child's medical home by involving primary and specialty health-care providers in supporting family participation in early intervention services.
- Assure equity of access, quality, consistency, and accountability in the service system by ensuring clear lines of public supervision, responsibility, and authority for the provision of early intervention services to eligible children and their families.

New York State Public Health Law designates the Department of Health as the lead agency for this statewide program. As the lead agency, the NYSDOH is responsible for the overall supervision and administration of the Early Intervention Program. Responsibilities include:

- Implementing statewide policies, procedures, and programmatic and reimbursement regulations.
- Implementing a comprehensive public awareness and child-find system.
- Approving, compiling, and disseminating lists of approved service coordinators, evaluators, and service providers.
- Providing training and technical assistance to municipalities and service providers to enable them to identify, locate, and evaluate eligible children; developing individualized family service plans; ensuring the appropriate provision of early intervention services; and promoting the development of new services where there is a demonstrated need.
- Safeguarding parent and child rights under the Early Intervention Program.
- Establishing and maintaining an Early Intervention Coordinating Council to advise and assist the Department in program implementation.

Early Intervention Policy ❖ Throughout the document, information about relevant Early Intervention Program policy is presented in boxes with this symbol.

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DOWN SYNDROME

ASSESSMENT AND INTERVENTION FOR YOUNG CHILDREN (AGE 0-3 YEARS)

This *Clinical Practice Guideline: Report of the Recommendations* presents the full text of all the recommendations plus an abbreviated description of the methodology and evidence used to develop the recommendations.

The full text of all the recommendations plus a description of the methodology and evidence used to develop the recommendations can be found in the *Clinical Practice Guideline: The Guideline Technical Report*.

An abbreviated version of the background information and guideline recommendations can be found in the *Clinical Practice Guideline: Quick Reference Guide*.

CHAPTER I: INTRODUCTION

PURPOSE OF THIS CLINICAL PRACTICE GUIDELINE

This guideline was developed by an independent multidisciplinary panel convened by the New York State Department of Health under the direction of the Bureau of Early Intervention. The New York State Department of Health sponsored the guideline development initiative with the broad goal of improving services to children within the Early Intervention system in New York State.

This clinical practice guideline on Down syndrome is intended to provide parents, professionals, and others with recommendations about "best practice" based on consensus opinion of the panel and scientific evidence about the efficacy of various assessment and intervention options for young children with Down syndrome.

The key elements of the guideline development approach include:

- Ensuring multidisciplinary representation
- Developing a guideline that is valid, objective, and credible
- Using a process that includes a combination of systematic review of the available scientific literature, expert clinical opinion, and parent input

This guideline represents the guideline panel's concerted attempt to find and interpret the available scientific evidence in a systematic and unbiased fashion. It is hoped that by using an evidence-based approach, the guideline provides a set of recommendations that reflect current best practices and will lead to optimal outcomes for children and their families.

The guideline recommendations suggest "best practices," not policy or regulation

The recommendations in this guideline are not intended to be regulations for the Early Intervention Program administered by the State of New York.

The guideline is intended as a set of recommendations that provide guidance about "best practices."

Practitioners and families are encouraged to use the information provided in this guideline recognizing that ***the care provided should always be tailored to the individual****.*

Not all of the recommendations will be appropriate for use in all circumstances. The decisions to adopt any particular recommendation must be made by the practitioner and the family in light of available resources and circumstances presented by individual children and their families.

REASONS FOR DEVELOPING THIS GUIDELINE

The primary reasons for developing a clinical practice guideline for young children with Down syndrome are to:

- Help children and their families learn about appropriate and effective services
- Provide an education and information resource for professionals
- Promote consistency in service delivery
- Facilitate productive communication among professionals
- Facilitate quality improvement in early intervention services
- Indicate where more research is needed

SCOPE OF THE GUIDELINE

This clinical practice guideline provides recommendations about best practices for assessment and intervention for young children with Down syndrome. The *primary topics* of this guideline are:

- *Down syndrome in children under three years of age*

The primary focus of the guideline is children with Down syndrome from birth to three years old. However, age three is not an absolute cutoff, since many of the recommendations in this guideline may also be applicable to somewhat older children.

- *Developmental disabilities related to Down syndrome*

The focus of the recommendations in this document is assessment and intervention for developmental disabilities associated with Down syndrome. While children with Down syndrome commonly have various health or medical conditions that are important to address, it is beyond the scope of this guideline to evaluate specific assessment and treatment for medical conditions (such as heart problems) often found in children with Down syndrome.

DEFINITION OF DOWN SYNDROME

The definition of Down syndrome, as defined for this guideline, is any child who is diagnosed as having Down syndrome, regardless of the child's specific karyotype pattern.

Early Intervention Policy ❖ In New York State, children with diagnosed conditions that are highly likely to affect development, such as Down syndrome, are eligible for early intervention services.

DEFINITION OF OTHER MAJOR TERMS

Definitions are given below for some important terms as they are used in this guideline:

Assessment This is the entire process of identifying and evaluating the child, including the activities and tools used to measure level of functioning, establish eligibility for services, determine a diagnosis, plan intervention, and measure treatment outcomes.

Family Family means the child's primary caregivers, who might include one or both parents, siblings, grandparents, foster care parents, or others usually in the child's home environment(s).

Parent(s)	The term *parent(s)* is used to mean the child's primary caregiver. The primary caregivers are those who have significant responsibility for the welfare of the child. The primary caregiver may be someone other than the mother or father of the child.
Professional	A professional is a provider of a professional service who is qualified by training, experience, licensure, and/or other state requirements to provide the intended service. The term is not intended to imply any specific professional degree or qualifications other than appropriate training and credentials. It is beyond the scope of this guideline to address professional practice issues.
Screening	Screening is intended to mean the early stages of the assessment process. Screening may include parent interviews or questionnaires, observation of the child, or use of specific screening tests. Screening is used to identify children who need more in-depth assessment.
Target Population	The target population is children with Down syndrome from birth to age 3 years. Throughout this document, the term *young children* is used to describe this target age group.
Young Children	This term is used broadly to describe the target age group for this guideline (children from birth to age 3 years).

Early Intervention Policy ❖ The terms assessment, parents, and screening are defined in regulations that apply to the Early Intervention Program (EIP) in New York State. See Appendix D, Early Intervention Program Information.

In New York State, the term used for professionals who are qualified to deliver early intervention services is "qualified personnel." *Qualified personnel* are those individuals who are approved to deliver services to eligible children, to the extent authorized by their licensure, certification or registration, and who have appropriate licensure, certification, or registration in the area in which they are providing services. See Appendix D, Early Intervention Program Information.

THE IMPORTANCE OF USING SCIENTIFIC EVIDENCE TO HELP SHAPE PRACTICE

Every professional discipline today is being called upon to document effectiveness. Professionals are increasingly asked to document that the approach used is effective in bringing about the desired outcomes. Those providing, receiving, or paying for services often want to know if there are other approaches, or modifications of existing approaches, that might produce better outcomes or similar outcomes at less cost. The difficulty in answering these

questions is that many times the effectiveness of the methods used in current professional practice has not been studied extensively or rigorously.

Guidelines based on a review and evaluation of the scientific literature can help professionals, parents, and others learn what scientific evidence exists about the effectiveness of specific clinical methods. When adequate scientific evidence can be found and systematically evaluated, it provides a balanced and objective approach for making informed decisions.

OVERVIEW OF THE METHODS USED TO EVALUATE THE EVIDENCE

This clinical practice guideline for young children with Down syndrome is part of a series of clinical practice guidelines being developed by the New York State Department of Health (NYSDOH) for assessment and intervention for young children with developmental disabilities. To develop these guidelines, the NYSDOH used a methodology similar to that used by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care Policy and Research (AHCPR), a part of the United States Public Health Service. Using the AHCPR methodology, a multidisciplinary panel of topic experts, general providers (both clinicians and educators), and parents of children with Down syndrome participated in a series of meetings to review the available research and develop guideline recommendations.

Scope of the guideline

The general scope of this clinical practice guideline is to evaluate assessment and intervention methods for young children (birth to 3 years) with Down syndrome with the primary focus being assessment and intervention related to developmental disabilities associated with Down syndrome. Given that there are not significant issues related to identifying children who are born with Down syndrome, the primary focus of the assessment chapter is the developmental assessment of young children with Down syndrome. Although some of the important considerations related to medical assessment and treatment for conditions commonly associated with Down syndrome are included, it is not the primary focus of this guideline.

Not all of the topics included in the guideline were appropriate for the literature search and review process. In general, a literature search and review of the evidence *was not done* when:

- The topic or method was not a primary focus of this guideline (such as specific medical interventions).

- There was an extensive literature search for a topic but the literature was either not specific to children with Down syndrome (such as oral-motor function and feeding) or the topic was generally not considered controversial.
- The topic was generally not the subject of scientific study (such as the importance of multidisciplinary team collaboration).

STRENGTH OF EVIDENCE RATINGS

Each guideline recommendation has been given a "strength of evidence" rating, which is designated by the letter **[A]**, **[B]**, **[C]**, **[D1]**, or **[D2]** in brackets immediately after the recommendation. The strength of evidence rating indicates the amount, general quality, and clinical applicability (to the guideline topic) of scientific evidence the panel used as the basis for that specific guideline recommendation.

[A] = **Strong evidence** is defined as evidence from two or more studies that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, with the evidence consistently and strongly supporting the recommendation.

[B] = **Moderate evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, and where the evidence supports the recommendation.

[C] = **Limited evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had moderate quality or applicability to the topic, and where the evidence supports the recommendation.

[D] = **Panel consensus opinion** (either [D1] or [D2]):

- [D1] = **Panel consensus opinion** based on information not meeting criteria for adequate evidence about efficacy on topics where a systematic review of the literature was done
- [D2] = **Panel consensus opinion** on topics where a systematic literature review was not done

Recommendations based on information from studies about the developmental characteristics are given Evidence Ratings noted with a subscript [$_{dc}$] following the Evidence Rating.

The methodology for determining adequate evidence is summarized in Appendix A.

A strength of evidence rating indicates the *type of information* used as the basis for the recommendation. The strength of evidence rating does not reflect the importance of the recommendation or whether it is a recommendation for or against use. For example:

- If there is strong evidence that an intervention is *effective*, then a recommendation *for use* of the method is given an **[A]** evidence rating.
- If there is strong evidence that an intervention is *not effective*, then a recommendation *against use* of the method is given an **[A]** evidence rating.
- If a systematic *literature review found no evidence* about the efficacy of an intervention, then the panel's recommendation either for or against use of this method is given a **[D1]** evidence rating to indicate this is based on panel consensus opinion.
- If a systematic *literature review was not done* for an intervention, then the panel's recommendation either for or against the use of that method is given a **[D2]** evidence rating to indicate this is based on panel consensus opinion.

USING SCIENTIFIC EVIDENCE AS THE BASIS FOR CLINICAL DECISIONS

Considerations about using scientific evidence to develop practice guidelines

In developing evidence-based recommendations, the process of reviewing the scientific literature to find evidence-based answers to specific clinical questions is challenging. Many times the specific clinical issue of interest may not have been studied extensively in well-designed studies of the type that can adequately determine if a clinical method is effective. At other times, even when well-designed studies have been done on a particular clinical topic, the study findings themselves may not present totally straightforward and unambiguous answers to the clinical questions of interest. Careful analysis of the studies and considerable judgment are always needed when using the findings of research studies to help in making informed clinical decisions and developing evidence-based recommendations.

In developing evidence-based recommendations, it is exceptional to find studies that evaluate exactly the clinical situations and types of subjects that are of interest. Therefore, it is almost always necessary to generalize to some extent in terms of the subject characteristics (such as age or IQ) and the clinical setting or the type of assessment or intervention method used. The research reviewed for this guideline was no exception.

In using research evidence to help make clinical decisions, the two primary considerations are the *quality* of the evidence and its clinical *applicability* to the question of interest.

Quality of the study

The quality of the study is primarily related to the study design and controls for bias: the higher the quality of the study, the more confidence we can have that the findings of the study are valid. Confidence in the study findings becomes even greater when multiple well-designed studies done by independent researchers find similar results.

Clinical applicability of the study

The clinical applicability of the study is the extent to which the study's results would also be expected to occur in a particular clinical situation of interest. The applicability of a study's findings is considered to be higher when the subject characteristics, clinical methods, and clinical setting are similar between the study and clinical situation of interest.

The usefulness of a study's findings to clinical decision-making relates to:

- The level of confidence in the results (based on the quality and amount of scientific evidence)
- The similarity of the study's subjects, clinical methods, and setting to the question of interest (i.e., its applicability)

Considerations about quality of studies

All of these considerations about using scientific evidence as the basis for clinical decisions apply to the evidence-based recommendations of this guideline. Many studies were found that evaluated issues related to the guideline topic; however, very few of these provided scientific evidence that met the minimal criteria for study quality. For some of the clinical questions of interest, several studies were found that met criteria for adequate evidence about efficacy. For other questions of interest, few or no studies were found that met such criteria.

There are numerous articles in the scientific literature that did not meet criteria for adequate evidence about efficacy, yet still contain valuable information. This would include articles that are case reports and case series (sometimes using pre- and posttest designs), as well as articles that primarily discuss theory or opinion. These articles often provide valuable insights that may be useful in clinical

practice, but they do not provide adequate evidence about the efficacy of specific clinical assessment or intervention methods. In many cases, information from articles and studies not meeting these evidence criteria was considered, but information from these sources was not included as evidence about efficacy and was not given as much weight in making guideline recommendations.

Considerations about applicability of studies

Of particular concern for this guideline was finding high-quality scientific studies that focused on children with Down syndrome under three years old. For some topics, studies were found that evaluated only children within the guideline's target population, but for other topics, the only studies found evaluated groups that included somewhat older children or some children with developmental disabilities other than Down syndrome.

As noted above, including children over three years old or with other developmental disabilities in a study does not affect the quality of the study or bias the results, but it may make the study's findings somewhat less applicable to the guideline topic. This was taken into account when making guideline recommendations, and information from high-quality studies that focused on children with Down syndrome under three years old were given more weight.

Judging the quality and applicability of the evidence

Due to the considerations above, the guideline panel needed to use significant judgment in evaluating the quality and applicability of the scientific evidence when using it as the basis for the evidence-based recommendations. Similar limitations and considerations apply to all evidence-based practice guidelines.

PEER REVIEW, PERIODIC REVISION, AND GUIDELINE VERSIONS

The peer review process

The draft guideline was sent to a variety of topic experts, generalist providers, and parents for peer review. Comments were solicited on the draft document, and the panel reviewed these comments before making final revisions in the guideline. Review comments were received from 57 external reviewers.

Guideline versions

There are three versions of this clinical practice guideline published by the New York State Department of Health. All versions of a guideline contain the same basic recommendations specific to the assessment and intervention methods

evaluated by the panel, but with different levels of detail describing the literature review methods and the evidence that supports the recommendations.

The three versions of the Clinical Practice Guideline are:

- *Clinical Practice Guideline: The Guideline Technical Report*

Includes the full text of the recommendations and related background information plus a full report of the research process and the evidence that was reviewed

- *Clinical Practice Guideline: Report of the Recommendations*

Includes the full text of all the recommendations and related background information plus a summary report of the research process and the evidence that was reviewed.

- *Clinical Practice Guideline: The Quick Reference Guide*

Provides a summary of guideline recommendations and background information

Periodic review and revision of the guideline

This guideline reflects the state of knowledge at the time of publication, but, given the inevitable evolution of scientific information and technology, it is the intention of the NYSDOH that periodic review, updating, and revision will be incorporated into an ongoing guideline development process.

CHAPTER II: BACKGROUND INFORMATION

WHAT IS DOWN SYNDROME?

Down syndrome, also known as Trisomy 21, is a chromosome abnormality that occurs in approximately 1 of every 1,000 live births in the United States and Europe (de la Cruz 1981). Trisomy 21 is commonly called Down syndrome because it was first identified in 1866 as a specific condition by John Langdon Down, the superintendent of a facility for children with mental retardation in England. He was the first person to make the distinction between children with hypothyroidism and another group of children he referred to as 'Mongoloids' (because he believed the children to be similar in appearance to the people of Mongolia). This name was eventually dropped and the condition became known as Down's Syndrome. In the 1970s it was further revised to Down syndrome in the United States, but in England it remains Down's Syndrome.

WHAT CAUSES DOWN SYNDROME?

It was not until 1959 that the genetic cause of Down syndrome was first discovered. Jean Lejeune and his colleagues reported that individuals who had the characteristic appearance of Down syndrome also had an extra partial or complete chromosome 21, hence the term, trisomy 21 (Latin for three bodies). A person with Down syndrome has three instead of the usual two copies of chromosome 21.

The extra chromosome 21 is considered the direct cause of Down syndrome; the indirect causes responsible for the extra chromosome are yet to be identified. However, Down syndrome is not caused by something the mother does (or does not do) during pregnancy.

Trisomy 21 can occur in one of three forms:

- *Meiotic nondisjunction:* An error occurs in the separation of the pair of 21 chromosomes during cell division in the process of formation of sperm or egg. A child with Down syndrome has 47 distinct chromosomes in every cell (as compared with the usual 46). This is the most common type; it accounts for approximately 95 percent of Down syndrome occurrences.
- *Translocation:* In approximately three percent of individuals with Down syndrome, the extra copy of chromosome 21 is attached (translocated) to another chromosome. The other chromosome may be a number 13, 14, 15, 21, or 22. With a translocation trisomy, there are 46 chromosomes in each cell plus extra 21 material attached to another chromosome. About half of the instances of translocation happen spontaneously (are not inherited). The

other half occur as the result of inheriting the translocated chromosome from a parent with a balanced translocation (the parent with the balanced translocation has only two chromosome 21s, the translocated chromosome 21 plus one normal chromosome 21).

- *Mosaicism:* Approximately two percent of people with Down syndrome have mosaicism. Mosaicism results when nondisjunction occurs during cell division (mitosis) at some point after formation of the embryo. This results in a mixture of cells, in which some cell lines have trisomy 21 and others have the typical chromosome complement. Which cell lines are affected and which are normal, and the proportion of normal to abnormal cells are factors which might affect the degree to which such an individual manifests the characteristics typically associated with Down syndrome.

HOW COMMON IS DOWN SYNDROME?

Down syndrome is a relatively common genetic disorder, occurring in about one of every 800 to 1,000 live births. The chance of having a baby with Down syndrome increases significantly with the mother's increasing age. For example, at age 35 (mother's age), the risk of having a child with Down syndrome is one in 400; at age 40, the risk is one in 110; at age 45, the risk is approximately one in 35 (National Down Syndrome Society). The risk of having a second child with Down syndrome is higher. If a parent is a balanced translocation carrier, the risk of having a child with Down syndrome may be as high as one in ten.

HOW IS DOWN SYNDROME DIAGNOSED?

A diagnosis of Down syndrome is confirmed by chromosome analysis. Diagnosis in the newborn or older individual is accomplished by chromosome analysis of lymphocytes (white blood cells) obtained from a blood sample. Prenatal diagnosis involves examination using fetal cells floating in the amniotic fluid (obtained by amniocentesis) or of cells taken from the placenta (chorionic villus sampling). Prenatal testing is usually performed when there is an increased risk of the fetus having Down syndrome. An increased risk might be indicated by increased maternal age, a prior family history of Down syndrome or a chromosome abnormality in the parent, or by abnormal levels of certain biochemical markers found on maternal blood screening.

In order to examine chromosomes, the cells are stimulated chemically to divide. The cell division is then arrested at the point at which the chromosomes are beginning to divide. The chromosomes are then stained so that they can be viewed, counted, and examined. For a permanent record, a picture can then be

taken and from the print, the chromosomes can be cut out and arranged in pairs in numerical order. The number and pattern of an individual's chromosomes is called a *karyotype* (see Figures 1-4).

Figure 1: Normal (Non-Down Syndrome) Karyotype

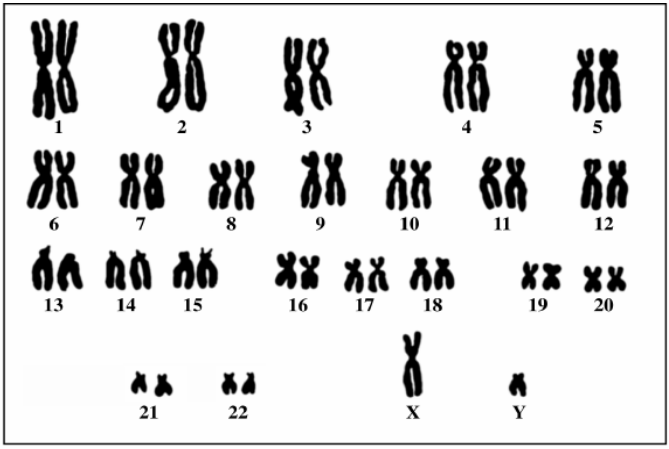


Figure 2: Nondisjunction Down Syndrome (extra free-standing 21)

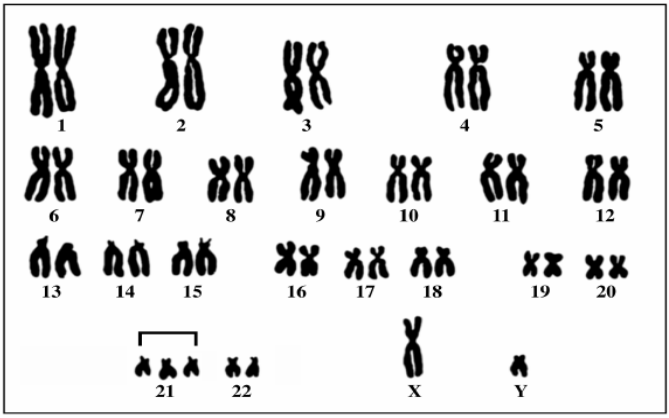


Figure 3: Balanced Translocation (a 21 is attached to a 14: no extra 21 material)

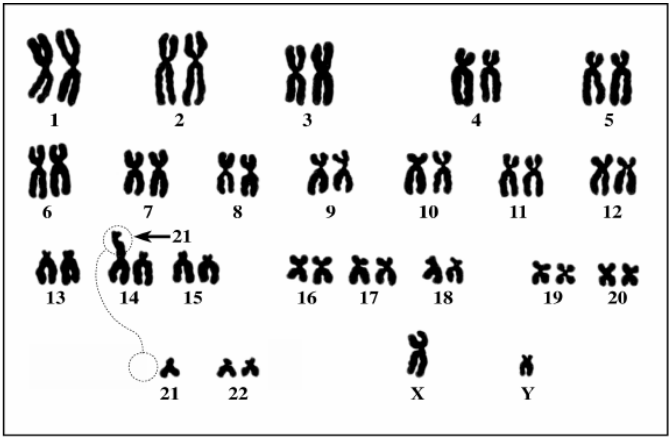
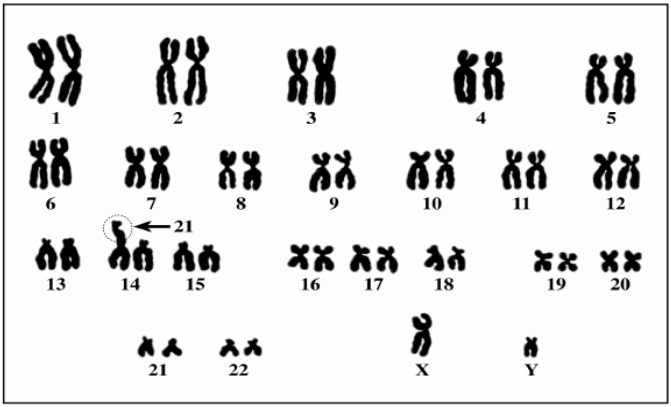


Figure 4: Translocation Down Syndrome (a third 21 is attached to a 14: three copies of 21)



WHAT ARE THE PHYSICAL AND DEVELOPMENTAL CHARACTERISTICS ASSOCIATED WITH DOWN SYNDROME?

The most common physical and developmental features of children with Down syndrome include:

Physical characteristics

- Diminished rate of growth and physical development. Most people with Down syndrome do not reach average adult height
- An atypical head shape. The head may be smaller than average (microcephaly), with a flat area at the back (occiput)
- Eyes that slant upward toward the edge of the face (upslanting palpebral fissures) and an excess fold of skin over the inner corner of the eyes (epicanthal folds)
- White (Brushfield) spots in the colored part of the eyes
- Small or overfolded ears, a flat nasal bridge, and a small mouth with low oral muscle tone and a protruding tongue
- Short, broad hands with short fingers and a single crease spanning the width of the palm (single palmar crease)
- Decreased muscle tone

Developmental characteristics

- Delayed cognitive development, usually within the mild to moderate range of mental retardation. An occasional individual, usually with a mosaic genotype, may have an IQ in the average range
- Delayed and atypical speech and language development, with expressive language being more delayed than receptive language
- Delayed development of social skills
- Delayed motor skills
- Possible coexistence of other developmental disorders, mental health or behavioral conditions (such as attention deficit hyperactivity disorder, oppositional defiant disorder, or pervasive developmental disorders/autism)

In addition to the general developmental delays that are characteristic of most children with Down syndrome, there may also be qualitative differences

between the development of children with Down syndrome and typically developing children. Furthermore, within a population of children with Down syndrome, as within any group of children, there will be considerable individual variability of development. It is important to recognize that all children with Down syndrome will have distinguishing strengths and talents as well as limitations.

WHAT MEDICAL PROBLEMS ARE ASSOCIATED WITH DOWN SYNDROME?

Children with Down syndrome are at risk for:

- Short stature.
- Congenital heart disease. More than 40 percent of children born with Down syndrome will have a congenital heart malformation.
- Frequent ear infections and other respiratory tract infections.
- Hearing loss. Infants and children may have a conductive loss as a result of middle ear effusion or structural abnormalities of the ear, a sensorineural loss, or both. Some people with Down syndrome may begin to develop hearing loss after 10 years of age. If undetected, this may significantly impact on all areas of development.
- Eye problems including refractive errors, strabismus, nystagmus, and cataracts. Congenital cataracts can lead to vision loss if not treated.
- Dental anomalies and gum disease.
- Thyroid function abnormalities (hypo- or hyperthyroidism) occur more frequently among individuals with Down syndrome.
- Obstructive airway disease. Symptoms include snoring, unusual sleeping positions, excessive fatigue or napping during the day, inattention and distractibility, or behavior changes.
- Increased mobility of the cervical spine between the first and second vertebrae (atlantoaxial instability). This condition is found by x-ray in approximately 14 percent of individuals with Down syndrome. Symptoms, occurring in about 1-2 percent of individuals with Down syndrome, include neck pain, unusual posturing of the head and neck, change in gait, loss of upper body strength, abnormal neurologic reflexes, and change in bowel/bladder function (Cohen 1996).

- Congenital defects of the gastrointestinal tract. These include duodenal atresia, an obstruction of the first segment of the small intestine.
- Higher incidence (but still only about 1 percent) of acute lymphoblastic leukemia than in the general population. In this condition, abnormally dividing white blood cells replace normal blood marrow elements, leaving the affected child susceptible to anemia, bleeding, and infection. Symptoms may include excessive bleeding and bruising, pinpoint red spots (petechiae), bone or joint pain, and enlarged lymph nodes.
- A tendency toward obesity.

WHAT TREATMENTS ARE AVAILABLE FOR DOWN SYNDROME?

There is no cure for Down syndrome. However, many of the specific health and medical conditions associated with Down syndrome can be corrected or improved with appropriate treatment. In the past few decades, advances in medical care have resulted in improved health and life expectancy for individuals with Down syndrome. It is also common that infants with Down syndrome are now referred to early intervention programs shortly after birth. The goal of intervention programs for children with Down syndrome is to maximize each child's developmental potential and improve long-term functional outcomes for children and their families.

Table 1: Common Associated Conditions in Children With Down Syndrome

	Percent of Children Affected
Congenital heart disease	40
Hearing loss	>60
Vision problems	
▪ cataracts	3
▪ refractive errors	70
▪ strabismus	50
▪ nystagmus	35
Dental problems:	
▪ hypodontia, malocclusion	>60
Hypothyroidism	>10
Gastrointestinal tract defect	12
Psychiatric disorders in adolescence	13

Table 1: Common Associated Conditions in Children With Down Syndrome

	Percent of Children Affected
Alopecia (hair loss)	10
Seizures	6
Leukemia	1

Adapted from: Pueschl 1990
(Continued from previous page)

Table 2: Common Characteristics of Children With Down Syndrome

Physical Characteristics	Developmental Characteristics
Short stature	Developmental Delay
Low muscle tone	▪ cognitive
Joint laxity	▪ motor
Flat facial profile	▪ communication
Upward slanting eyes	▪ social skills
Abnormal shape of the ears	▪ adaptive/self-help
Little finger with only one joint	
A single deep crease across the palm	
Obesity	

MYTHS AND FACTS *

Myth: Most children with Down syndrome are born to older parents.

Fact: Although the incidence of Down syndrome increases with maternal age, 80 percent of children with Down syndrome are born to women younger than 35 years of age.

Myth: People with Down syndrome are severely retarded.

Fact: The functional level of most people with Down syndrome fall within the mild to moderate range of mental retardation.

Myth: Children with Down syndrome should be institutionalized.

Fact: Most children with Down syndrome live at home with their families, participate in community activities, participate in regular education services, do sporting activities, and develop skills for independent living.

Myth: Children with Down syndrome have to be placed in segregated special education settings.

Fact: The Individuals with Disabilities Education Act (IDEA) requires that children with disabilities receive early intervention services in natural environments and educational services in the least restrictive settings. The appropriate level of integration depends on the ability of the child and the level of supports and services available. This would include participation in activities in natural environments (for infants and toddlers), in regular preschool and day care programs (for preschoolers), and regular classrooms (for school-age children).

Myth: People with Down syndrome cannot form close, intimate relationships.

Fact: People with Down syndrome can date and form on-going relationships. Some may decide to marry. A woman with Down syndrome can have children, but there is a 50 percent chance that the children will have Down syndrome. There has been only one documented case of a male with Down syndrome being fertile.

** Myths and Facts adapted from information provided by The National Down Syndrome Society.*

WHERE CAN I GET MORE INFORMATION?

NDSS: The National Down Syndrome Society, founded in 1979, is a not-for-profit organization. It is the largest nongovernmental supporter of Down syndrome research in the United States.

National Down Syndrome Society
666 Broadway, 8th Floor
New York, NY 10012-2317

1-(800) 221-4602 (toll-free)
(212) 460-9330 (tel)
(212) 979-2873 (fax)
Website: http://www.ndss.org

NDSC: The National Down Syndrome Congress is a not-for-profit membership organization that serves as a national resource for families who have children with Down syndrome, professionals, and interested others.

National Down Syndrome Congress
1370 Center Drive
Suite 102
Atlanta, GA 30338

1-(800) 232-6372 (toll-free)
(770) 604-9500 (tel)
(770) 604-9898 (fax)
Website: http://www.NDSCcenter.org

DSPN: The Down Syndrome Parent Network is an organization whose goal is to provide accurate, up-to-date information on Down syndrome to parents, families, professionals, and the general public.

Down Syndrome Parent Network
3626 Church Road
Easton, PA 18045

(800) HELP-309 (toll-free)
Website: http://www.dspn.org

Additional resources are listed in Appendix E.

Note: *Inclusion of these organizations is not intended to imply an endorsement by the guideline panel or the NYSDOH. The guideline panel has not specifically reviewed the information provided by these organizations.*

CHAPTER III: ASSESSMENT

Topics included in this chapter

- General Approach for Assessing Young Children With Down Syndrome
- Identification and Diagnosis of Down Syndrome
- The Developmental Assessment of Young Children With Down Syndrome
- Assessing the Resources, Priorities, and Concerns of the Family
- Health Evaluations of Young Children With Down Syndrome

ASSESSMENT ISSUES FOR YOUNG CHILDREN WITH DOWN SYNDROME

For young children with Down syndrome, early identification and definitive diagnosis are generally not a major issue since children with Down syndrome can usually be identified at birth, or shortly thereafter, and the diagnosis can be confirmed by chromosome analysis. Therefore, the focal points of the assessment chapter for young children with Down syndrome are:

- The developmental assessment (assessing the child's strengths, needs, and individual developmental styles in various domains)
- Early identification and assessment of various health problems often associated with Down syndrome

Understanding the developmental characteristics of young children with Down syndrome

When assessing young children with Down syndrome, it is important to understand that young children with Down syndrome share some common developmental characteristics that differ from typically developing children and/or from children with other developmental disabilities. Understanding some of these common characteristics makes it possible to more accurately assess the developmental status and measure the progress of a child with Down syndrome compared with other children with Down syndrome. Understanding some of the developmental characteristics of young children with Down syndrome makes it possible to plan more appropriate assessments, to provide anticipatory guidance, and to develop more specific and effective interventions.

Similarly, when assessing young children with Down syndrome, it is equally important to understand that they also have individual personalities and

individual developmental characteristics that make one child with Down syndrome different from another child with Down syndrome.

GENERAL APPROACH FOR ASSESSING YOUNG CHILDREN WITH DOWN SYNDROME

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

General Considerations for Assessing Children With Down Syndrome

Because Down syndrome is a genetically confirmed condition that can be definitively diagnosed before birth, at birth, or shortly thereafter, there is little need for a lengthy discussion of how to identify and diagnose children with Down syndrome. The assessment chapter of this guideline, therefore, focuses primarily on developmental assessments of young children with Down syndrome, assessing the strengths and needs of the family, and general health assessments. This section of the assessment chapter presents general considerations for these assessments.

Early Intervention Policy ❖ Children with Down syndrome are eligible for the Early Intervention Program (EIP) by having a diagnosed condition with a high probability of developmental delay.

Health-care providers, including physicians and nurses, are primary referral sources under NYS public health law, and are responsible for referring children and their families who are eligible for early intervention services to the Early Intervention Official (EIO) in their county of residence. Parents of infants with Down syndrome should be informed about early intervention services as soon as possible after birth, and a referral should be made to the EIO unless the parents object.

Recommendations (General Considerations for Assessing Children With Down Syndrome)

Importance of early identification and intervention

1. It is important to identify children with Down syndrome and begin appropriate intervention as soon as possible. Early assessment and

intervention may help to support the child's general development and lead to better long-term functional outcomes.

[C_{dc}] (Carr 1970, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Sanz 1996, Sloper 1986)

2. When Down syndrome is diagnosed, it is important to initiate an assessment process to determine appropriate interventions to address all developmental domains. It is appropriate to begin this process at the time of diagnosis.

   [C_{dc}] (Carr 1970, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Sanz 1996, Sloper 1986)

3. It is not necessary to wait for a demonstrated developmental delay to initiate an ongoing assessment and intervention process for young children with Down syndrome.

   [C_{dc}] (Carr 1970, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Sanz 1996, Sloper 1986)

Early Intervention Policy ❖ All children referred to the Early Intervention Program (EIP) must receive a multidisciplinary evaluation to establish eligibility and to help develop an Individualized Family Service Plan (IFSP). The multidisciplinary evaluation is important to understanding the child's developmental status and priorities, resources, and concerns of the family.

The terms multidisciplinary evaluation, assessment, and parents are defined in regulations that apply to the EIP in New York State. These definitions are included in Appendix D.

General assessment considerations

4. When assessing young children with Down syndrome, it is important for those assessing the child to understand the whole child and to take into consideration any factors, such as health conditions, that may have an impact on the child's performance during the assessment process. It is important to ensure that the child has had an adequate evaluation of:
   - Health status
   - Hearing status
   - Vision status [D2]

5. It is recommended that the assessment materials and strategies be developmentally appropriate. [D2]

6. It is important that the assessment be viewed as an ongoing process that follows the child over time rather than as a single event. [D2]

7. It is recommended that the setting in which the assessment is performed be appropriate to the developmental stage of the child and be comfortable for both parent and child. The following are important environmental considerations:
   - Accommodating the child's schedule
   - Creating an enjoyable, engaging, positive experience
   - Providing a nondistracting, quiet environment (this may provide an opportunity to maximize the child's performance, but may not provide for a typical performance)
   - Having a parent or caregiver present
   - Accommodating the family's cultural orientation, including language [D2]

Importance of receiving accurate information

8. It is important for all parents and other primary caregivers to receive accurate information about their child with Down syndrome to allow them to:
   - Participate as active partners with health-care providers in monitoring the overall development and health of their child.
   - Become informed advocates for their child
   - Develop informed expectations about their child's development [D2]

Early Intervention Policy ❖ When families are referred to the Early Intervention Program (EIP), an initial service coordinator is assigned by the Early Intervention Official (EIO) to assist the family in obtaining a multidisciplinary evaluation. The multidisciplinary evaluation team is responsible for informing the parent(s) about the results of the child's evaluation. The multidisciplinary evaluation team should also provide the family with information about the development of children with Down syndrome – for example, by discussing information in these clinical practice guidelines and other sources of information.

Considering the cultural and family context

9. A child's life is embedded within a cultural and family context. When assessing children with Down syndrome, it is essential to consider:

- The family's ethnic and cultural background
- Parent priorities
- Parenting styles
- Family composition (e.g., parents, siblings)
- Family support systems [D2}

10. In evaluating children with Down syndrome, it is important to recognize that there may be cultural and familial differences regarding children with disabilities as well as the family's expectations about such things as play and social interaction, eye contact, pragmatic use of language, and the development of adaptive or self-help skills. [D2]

Early Intervention Policy ❖ The multidisciplinary evaluation must be performed in the dominant language of the child whenever it is feasible to do so.

11. If English is not the family's primary language, it is important for professionals to look for ways to communicate effectively with the family and the child, including involvement of professionals and/or translators who speak the primary language of the child and the family. [D2]

General Considerations for Professionals

Children with Down syndrome generally have some delay in all developmental domains, and they are at high risk for many different medical problems. As such, it is likely that there will be many different professionals involved in an ongoing process of assessment and intervention for these children. This section includes general consideration recommendations for the professionals who work with children with Down syndrome and their families.

Recommendations (General Considerations for Professionals)

1. It is important for health-care professionals (physicians, nurses, therapists, physician assistants, and other health-care professionals) to know about common associated health conditions in children with Down syndrome and to understand typical development in children with Down syndrome in order to:
   - Raise concerns and facilitate recognition and diagnosis of medical conditions that may need treatment

- Facilitate the use of appropriate developmental surveillance methods
- Give accurate information to parents and families
- Assist in making appropriate referrals
- Provide medical information and act as a liaison between the family and other service providers related to the child's health-care needs [D2]

Early Intervention Policy ❖ Health-care providers and early childhood professionals are primary referral sources for the Early Intervention Program (EIP) under NYS public health law.

2. It is important that early childhood professionals (teachers, administrators, and paraprofessionals working in day care, preschool, and other early childhood settings) and therapists receive information about children with Down syndrome in order to:
   - Make appropriate observations about the child's development
   - Give accurate information to parents and families
   - Assist in making appropriate referrals
   - Facilitate appropriate intervention strategies [D2]
3. It is important that professionals assessing young infants with Down syndrome be knowledgeable and experienced. It is important that the professional:
   - Have a solid understanding of typical newborn and early development
   - Have a solid understanding of atypical patterns of development
   - Understand the importance of observation
   - Know how to take cues from the child
   - Know how to elicit the concerns of parents
   - Understand the importance of being sensitive to parents
   - Have expertise in administering the assessment tools so there is little or no need to reference them repeatedly through the evaluation. Evaluators need to be focused on the infant/child and his or her caregiver(s), not on the assessment tool
   - Know how to clean, maintain, and use the testing tools and equipment to ensure the health and safety of the child [D2]

Early Intervention Policy ❖ In New York State, the term used for professionals who are qualified to deliver early intervention services is "qualified personnel." *Qualified personnel* are those individuals who are approved to deliver services by the Early Intervention Program to the extent authorized by their licensure, certification, or registration to eligible children and for individual providers, their experience with infants and toddlers with disabilities. See Appendix D for the list of qualified personnel included in program regulations.

IDENTIFICATION AND DIAGNOSIS OF DOWN SYNDROME

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

Physical Findings at Birth

Clues or signs that an infant might have Down syndrome are usually apparent at birth. There are many physical characteristics that are more common among infants with Down syndrome than among those who do not have Down syndrome. The most common of these signs are called cardinal signs (see Table 3). If a newborn shows more than six cardinal signs, it is very probable that Down syndrome is present. However, confirmation comes only through chromosome analysis.

Table 3: Hall's Ten Signs of Down Syndrome in Newborns

Neonatal sign	% Frequency (percent of newborns affected)
Poor Moro reflex	85
Hypotonia	80
Flat facial profile	90
Upward-slanting palpebral fissures (eyelid openings)	80
Morphologically simple, small round ears	60
Redundant loose neck skin	80
Single palmar crease	45
Hyperextensible large joints	80

Table 3: Hall's Ten Signs of Down Syndrome in Newborns

Neonatal sign	% Frequency (percent of newborns affected)
Pelvis radiograph morphologically abnormal	70
Hypoplasia of fifth finger middle phalanx	60

Adapted from: Tolmie 1998
(Continued from previous page)

General Description of Neonatal Signs of Down Syndrome

Poor Moro reflex	The baby's muscles don't tighten when body support is suddenly withdrawn
Hypotonia	Low muscle tone, floppiness
Flat facial profile	The bridge of the nose tends to be low and the cheekbones high, which makes the face look flat and the nose look small
Upward-slanting palpebral fissures	The eyes have an upward and outward slant
Morphologically simple, small round ears	Ears tend to be small, low-set, and have very small or absent earlobes
Redundant loose neck skin	The neck often appears slightly short with loose skin folds at the sides and back
Single palmar crease	A single crease across the palm, either on one hand or both hands
Hyperextensible large joints	A tendency for loose joints
Pelvis radiograph morphologically abnormal	X-ray of the pelvis shows that the pelvis is rather small and the bones less developed than in infants who do not have Down syndrome
Hypoplasia of fifth finger middle phalanx	The middle section of the little finger is short

Confirming the Diagnosis by Chromosome Analysis

A diagnosis of Down syndrome is confirmed by chromosome analysis. Diagnosis in the newborn or older individual is accomplished by looking at lymphocytes (white blood cells) obtained from a blood sample. Prenatal diagnosis involves examination of fetal cells floating in the amniotic fluid (obtained by amniocentesis) or of cells taken from the placenta (chorionic villus sampling). Prenatal testing is usually performed when there is an increased risk

of the fetus having Down syndrome. An increased risk might be indicated by increased maternal age, a prior family history of Down syndrome or a chromosome abnormality in the parent, or by abnormal levels of certain biochemical markers found on maternal blood screening.

In order to examine chromosomes, the cells are stimulated chemically to divide. The cell division is then arrested at the point at which the chromosomes are beginning to divide. The chromosomes are then stained so that they can be viewed, counted, and examined. For a permanent record, a picture can then be taken and from the print, the chromosomes can be cut out and arranged in pairs in numerical order. The number and pattern of an individual's chromosomes is called a *karyotype*.

A person with Down syndrome has three copies of chromosome 21 instead of the usual two (see illustrations, page 16). Hence Down syndrome is also known as trisomy (Latin for three bodies) 21. Trisomy 21 can occur in one of three forms:

- *Meiotic nondisjunction*s: An error occurs in the separation of the pair of chromosome number 21 during cell division in the process of formation of sperm or egg. The affected individual has 47 distinct chromosomes in every cell compared with the usual 46. This is the most common situation, accounting for 95 percent of instances of Down syndrome.
- *Translocation*: In approximately three percent of individuals with Down syndrome the extra copy of chromosome 21 is attached (translocated) to another chromosome. The other chromosome may be a number 13, 14, 15, 21, or 22. Thus, the affected individual has 46 chromosomes in each cell, plus extra 21 material. About half of the instances of translocation are *de novo* (occurring for the first time, not inherited), but half are inherited from a parent with a balanced translocation. The parent with the balanced translocation does not have Down syndrome because he or she has only two chromosome number 21.
- *Mosaicism:* Approximately two percent of people with Down syndrome have mosaicism. Mosaicism results when nondisjunctions occur during cell division (mitosis) at some point *after* formation of the embryo. This results in a mixture of cells, in which some cell lines have trisomy 21 and others have the typical chromosome complement. Which cell lines are affected and which are normal, and the proportion of normal to abnormal cells are factors that affect the degree to which such an individual has the characteristics of Down syndrome.

Communicating the Diagnosis to Parents

When a child is diagnosed as having Down syndrome, the news is likely to be unexpected. There are many factors that may influence how the parents respond when information about the diagnosis is communicated. For example, when, where, and how this information is delivered to the parent can have a significant impact on the initial reaction and the process of adjusting to the diagnosis. The following were identified by parents as factors that influenced their reactions to learning that their child had been diagnosed as having Down syndrome (Garwick 1995).

Factors important to parents

- Characteristics of the condition
- Preexisting family factors (e.g., condition of the mother and infant at the time of diagnosis, previous knowledge and beliefs about the condition)
- The setting in which the family was informed
- The manner in which the health-care professionals initially informed them
- The quality of the information provided

Parents' preference for receiving the news about the diagnosis

- In person rather than over the telephone
- With both parents present
- In a setting that has privacy

Helpful informing strategies

- Focusing on the child as a whole, rather than only on the negative aspects of Down syndrome
- Being supportive and sensitive to the parents' feelings
- Providing appropriate resources and relevant, up-to-date information about the child's condition

Recommendations (Communicating the Diagnosis to Parents)

1. As soon as the diagnosis of Down syndrome is suspected, it is recommended that the physician communicates this information to the parents. [D2]

2. It is recommended that the physician discuss the diagnosis of Down syndrome with both parents at the same time, in person and, if possible, in private rather than in the presence of strangers (such as a hospital roommate). [D2]
3. How the diagnosis is communicated is important. It is important to deliver the news in a sensitive and caring way that supports the family, as this may help to provide the foundation for a strong relationship between parents and the child, the parents and the extended family, and the parents and service providers. [D2]
4. It is important that those professionals who may be delivering the news about the diagnosis have specific training in how to discuss serious health problems and conditions with parents and families. It is also important for clinical teams to discuss how this will be done and to develop a plan for staff training, evaluation, and self-assessment. [D2]
5. As soon as possible after the diagnosis is made and when the parents are ready, it is recommended that parents be given:
   - Current facts and information about Down syndrome
   - Referrals to appropriate resources, such as the Early Intervention Program and appropriate health-care specialists [D2]
6. It is important to avoid negative labeling of the condition, the child, or his or her developmental potential. [D2]
7. It is important that parents have the opportunity to ask questions and have a discussion that is not hurried or rushed with a health-care professional at the time of diagnosis. [D2]
8. It is important that professionals listen to the individual family's reaction to the diagnosis so that appropriate support and information can be provided. [D2]
9. It is important to understand that not all families will have the same reaction. [D2]
10. When informing parents that their child has Down syndrome, it is important to recognize that parents of children with disabilities often hold themselves accountable, or feel they are held accountable by others, for their child's disability. It is important to provide information to the parents about the etiology (cause) of Down syndrome and to let the parents know that it is not the result of anything that either of the parents did or did not do prenatally. [D2]

11. It is important to recognize that parents may react differently to an uncertain prognosis about the child's developmental potential. Some parents may find it stressful; for others, uncertainty provides hope. The physician wanting to prepare the parents for the worst may be inadvertently eliminating hope and setting up an adversarial relationship between the doctor and the parents. [D2]

12. When communicating with the parents about the diagnosis, it is important for health-care professionals to focus on:
    - The child as an individual and member of the family
    - The positive individual attributes, strengths, and characteristics of the child
    - That fact that the child will learn, grow, and develop
    - Ways in which the child will be similar to typically developing children [D2]

13. It is important to discuss the opportunities for follow-up and ongoing support with parents, including counseling and other support services such as:
    - Social work
    - Psychological counseling
    - Pastoral counseling
    - Parent-to-parent support
    - Parent support and education groups [D2]

Early Intervention Policy ❖ Health-care providers are primary referral sources. It is their responsibility to inform parents about the Early Intervention Program (EIP) and the benefits of early intervention services. Health-care providers must offer to refer or assist the family in making a referral to their Early Intervention Official (EIO), or parents can choose to contact an EIO directly. See Appendix D for a list of Early Intervention Program phone numbers.

14. When clinicians deliver the news about Down syndrome, it may be helpful to follow these steps (PACE) (Garwick 1995):
    - **P**lan the situation and setting in which the family is informed
    - **A**ssess preexisting family factors such as the parents' previous knowledge about and experience with Down syndrome

- **C**hoose the information and emotional support strategies that meet the needs of the particular family
- **E**licit feedback from the family about their understanding of the news [D2]

THE DEVELOPMENTAL ASSESSMENT OF YOUNG CHILDREN WITH DOWN SYNDROME

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

General Approach to Developmental Assessment

A developmental assessment for children for age birth to 3 years is an attempt to assess various aspects of the child's functioning in all environments. There is no doubt that children with Down syndrome have *quantitative* delays in many aspects of development when compared with typically developing children. While children with Down syndrome generally tend to follow the same developmental sequence as typically developing children, their development is usually delayed when compared with typically developing children. In addition to quantitative delays, current research suggests that children with Down syndrome appear to develop and function in ways that are *qualitatively* different from other children with developmental delays. These differences show themselves in particular styles of learning, communication, and social interaction that may be unique, or at least much more common, among children with Down syndrome. It is important to recognize and understand these similarities and differences when assessing young children with Down syndrome.

As with all children, the developmental assessment includes:

- Cognition
- Communication (receptive and expressive language)
- Physical (fine and gross motor and sensory processing abilities)
- Social emotional/social interaction
- Adaptive and self-help skills

Recommendations (General Approach to Developmental Assessment)

Importance of the developmental assessment

1. Because young children with Down syndrome tend to be delayed in all areas of development compared with typically developing children, it is important that all children with Down syndrome have periodic, ongoing, age-appropriate developmental assessments in all developmental domains. [D2]

Early Intervention Policy ❖ A multidisciplinary evaluation must assess all five areas of development (cognitive, communication, physical, social/emotional, and adaptive development). The multidisciplinary evaluation is provided at no cost to parents. Ongoing assessment of a child's progress should be performed as part of early intervention service delivery.

2. Developmental assessments are important because they will provide:
   - An objective description of the child's abilities and needs
   - A framework for developing appropriate interventions
   - A baseline against which progress and effects of intervention can be measured over time [D2]

General considerations

3. It is important for professionals to consider how the assessment process and results will impact on the family. [D2]
4. It is important to understand the whole child and to take into consideration any factors that may have an impact on the child's performance during the developmental assessment, such as the child's health status, and hearing and vision status. [D2]
5. It is important to use any prescribed hearing and vision aids for the child to perform optimally. [D2]
6. It is important to provide appropriate postural support when assessing young children with Down syndrome and to make appropriate accommodations for any motor limitations. For example, consider:
   - Appropriate positioning
   - Need for head, trunk, and foot support

- Appropriate table height, seat depth, and width [D2]

7. It is important that the developmental assessment be viewed not as a single event but as an ongoing process that follows the child over time. [D2]

Conducting the developmental assessment

8. Since Down syndrome is usually identified early, it is important that a general assessment of all developmental domains be done in the first three months of life. It is not necessary to wait until delays are demonstrated. [D2]

Early Intervention Policy ❖ Children with Down syndrome are eligible for the Early Intervention Program (EIP) because they have a diagnosed condition with a high probability of developmental delay. Services may begin before a quantified developmental delay is evident.

9. When assessing young children with Down syndrome, it is important to recognize qualitative differences. A good developmental assessment includes qualitative evaluation, quantitative measures, and observation. It is important that the assessment not be limited to measuring only quantitative differences. For example, in addition to looking at a child's developmental level, it is also important to look at how the child completes each task. [D2]

10. It is important that the developmental assessment:
    - Be individualized for each child
    - Use age-appropriate testing and scoring methods
    - Consider the child's individual abilities and needs, including specific discrepancies in functioning across and within developmental domains
    - Make use of the parents' observations of their child [D2]

11. It is important that the developmental assessment of young children with Down syndrome be a multimodal, multimethod assessment, including:
    - Multiple settings, as appropriate, such as the home, day care setting, school, and typical social environments
    - Multiple modalities (such as pictures, objects, sounds)
    - Multiple examiners (teachers, therapists) [D2]

Early Intervention Policy ❖ The multidisciplinary evaluation team can use a combination of standardized instruments and procedures, and informed clinical opinion to determine a child's eligibility for services.

The multidisciplinary evaluation team must include professionals relevant to the needs of the child and family and must include at least two qualified personnel of different disciplines. The multidisciplinary evaluation must be performed using nondiscriminatory procedures as defined in program regulations (see Appendix D) and be conducted in the child's dominant language whenever feasible.

12. It is recommended that assessment be an ongoing process that occurs in more than one session and in more than one setting, as appropriate, because:
    - The child's performance may vary depending on familiarity with the environment and the professional
    - The child's comfort level with the professional may change over time
    - A child's performance can vary from day to day and may vary according to the time of day (morning versus afternoon, for example) [D2]

Early Intervention Policy ❖ Ongoing assessment should be included as part of ongoing early intervention services by all qualified personnel working with the child and family.

13. Developmental assessments can be performed by a variety of professionals in a number of settings. In order to assure quality and consistency, it is recommended that professionals participating in the developmental assessment:
    - Have experience and expertise in assessing young children with Down syndrome
    - Use normed and standardized tests as well as observational information
    - Use procedures that are reproducible by other professionals [D2]
14. It is recommended that when assessing children with Down syndrome, the language used with the child be concrete and specific. [D2]
15. It is important to include observational data obtained in the child's natural environment. [D2]
16. It is important to note whether any testing modifications were used. [D2]

Special considerations for assessing young children

17. It is important to consider general and specific child and family factors when planning for and conducting developmental assessments. Table 4 lists some of the special considerations for assessing young children. [D2]

Table 4: Considerations for Planning and Conducting Assessments for Young Children

Planning the Assessment

- Ensure that professionals are experienced with this age group
- Make sure that the parents are available to be present for the assessment
- Ask the parents what their needs and expectations are for the assessment process
- Be aware of and informed about medical conditions that might influence the infant's tolerance for the assessment process
- Take the child's sleep/wake/alert routines into consideration
- Allow for extra time in the evaluation process for necessary baby care or child care, such as feeding and diapering

Conducting the Assessment

- Explain each step of the assessment process before it is performed, and provide an explanation for why each aspect of the assessment is needed
- Be sensitive to parent and child needs and reactions during the assessment process
- Take cues from the parent in setting the pace of the assessment process (allowing time for breaks, for example)
- Be sensitive to the family's current life/work issues (such as adjusting to having a new baby, for example)
- Encourage parent observations of the child's developmental status and temperament
- Provide opportunities for the parent to discuss concerns and information needs
- Be aware of the need for (and provide) postural control and support
- Be alert to signs of other medical problems that may not have been identified
- Begin the assessment with the child in positions that are comfortable for the child. Save tests that the child may not like, such as range of motion or protective responses, for the end of the assessment
- Attend to biologic cues/behavior/evidence of overstimulation or responses to stress (such as crying, yawning, hiccupping, irritability)
- Be aware that very young infants may have difficulty regulating body temperature
- Provide feedback to the family about the assessment findings

Components of the developmental assessment

18. It is recommended that a developmental assessment for a young child with Down syndrome provide an adequate functional profile of all developmental domains. Important components of a developmental assessment include:
    - Information about the child's early developmental and medical history, and current level of functioning obtained from:
        - Parent reports and interviews
        - Medical records (including input from the primary care provider and any specialists that may be involved)
        - Child care and other relevant records
    - Standardized tests, where appropriate, of:
        - Cognitive ability
        - Communication (receptive and expressive language)
        - Social skills
        - Motor skills
        - Adaptive/self-help skills
        - Behavior and temperament

        [Commonly used developmental tests are described in Appendix C.]
    - Direct observation of the child:
        - When interacting with parents, siblings, and others
        - At informal and structured play
        - Information about the family resources, priorities, and concerns [D2]

Early Intervention Policy ❖ The early intervention multidisciplinary assessment must include an assessment of all five areas of development (cognitive, communication, physical, social/emotional, and adaptive development) and a parent interview. Families may also participate in an optional family assessment.

The multidisciplinary evaluation team must complete the child's evaluation in accordance with requirements in NYS Public Health Law and regulations, and standards and procedures for evaluation and eligibility issued by the Department. The multidisciplinary evaluation is provided at no cost to parents.

19. It is important to include a curriculum-linked assessment as a component of the developmental assessment. A curriculum-linked assessment consists of items/tasks that are associated with a course of intervention. Curriculum-linked assessments are appropriate when setting goals and objectives for interventions, and when assessing attainment of specific skills. [D2]

Assessing developmental milestones

20. When assessing a child with Down syndrome, it is important to consider the child's development relative to both children with Down syndrome and typically developing children (Tables 4 through 7). This is important because it gives parents and others caring for children with Down syndrome:
    - A better understanding of the developmental status of an individual child
    - Help in making appropriate decisions about the focus, timing, and sequence for interventions
    - Reference points for determining if a child falls outside the expected range of development for children with Down syndrome

    [C_{dc}] (Carr 1970, Caselli 1998, Cobo-Lewis 1996, Lynch 1995, Haley 1986, Haley 1987, Harris 1983, Mahoney 1981, Mundy 1988, Rast 1985, Steffens 1992)

21. When assessing children with Down syndrome, it is important to recognize that there will be individual differences as to when specific developmental milestones are attained.

    [C_{dc}] (Carr 1970, Caselli 1998, Cobo-Lewis 1996, Lynch 1995, Haley 1986, Haley 1987, Harris 1983, Mahoney 1981, Mundy 1988, Rast 1985, Steffens 1992)

22. When evaluating milestones as indications of developmental level in young children with Down syndrome, it is important to look for:
    - Specific developmental areas in which the child is delayed more than expected for children with Down syndrome
    - Specific developmental areas in which the child is advanced more than expected for children with Down syndrome
    - Developmental levels in different domains that are significantly discrepant within an individual child

    [C_{dc}] (Carr 1970, Caselli 1998, Cobo-Lewis 1996, Lynch 1995, Haley 1986, Haley 1987, Harris 1983, Mahoney 1981, Mundy 1988, Rast 1985, Steffens 1992)

Considerations in deciding on assessment strategies, materials, and settings

23. It is recommended that assessment strategies and materials be developmentally appropriate for young children with Down syndrome and that the setting be appropriate and comfortable for the child and parents. [D2]

24. It is important to recognize that standardized developmental tests are usually not normed for children with Down syndrome. Standardized tests may provide information about how a child's performance compares with that of typically developing children, but may not be as useful for understanding how a child's development compares with that of other children with Down syndrome. [D2]

25. It is important to recognize that no child is "untestable." However, some tests may not be appropriate for some children. It is important to use appropriate testing materials and strategies for each child. [D2]

Including the parents in the assessment process

26. It is recommended that a parent or other primary caregiver be present for the formal assessment and that there be an opportunity for other family members to participate in the process. [D2]

27. It is recommended that assessment include information from a parent report of the child's performance in the child's natural settings. [D2]

Children with hearing, vision, or motor delays

28. When selecting assessment materials and procedures, it is recommended that the child's sensory capacities and modes of responding be taken into

account. For example, if a young child has significant limitations in hearing, vision, or motor abilities, it may be necessary to adapt materials, the setting, or testing/response procedures. The input of parents and others who know the child well can be extremely important in determining the most appropriate materials, procedures, and adaptations to be used. [D2]

Using the findings of the developmental assessment

29. It is important to follow up on questionable or abnormal findings from the developmental assessment of any young child. This might include adding elements to the developmental assessment and/or referring the child to other professionals for more detailed evaluation and specific diagnosis. [D2]

30. It is recommended that the findings of the developmental assessment be used in developing any intervention plans for the child. The developmental assessment also provides useful objective reference points for monitoring the progress of the child and assessing the outcomes of interventions. [D2]

31. It is important to use the results of the developmental assessment in ways that will help and encourage families to recognize the child's potential. [D2]

Communicating findings to parents and other professionals

32. It is recommended that a timely explanation of the results of the assessment be provided to the family (with translation into the child's and family's dominant language when needed). It is useful to discuss:
    - Important terms and concepts
    - The results and implications of the assessment
    - The child's performance level compared with developmental norms and the child's performance compared with that of other children with Down syndrome [D2]

Early Intervention Policy ❖ The multidisciplinary evaluation team is responsible for sharing the results of the evaluation with the child's family and ensuring the family understands the results and implications of the evaluation for intervention. The multidisciplinary evaluation team must also prepare a formal report and evaluation summary and submit the report to the Early Intervention Official.

33. It is recommended that assessment reports include:
    - Results presented in language that is understandable to the family and other professionals working with the child
    - Strengths and limitations of the assessment tools or processes
    - Information about how the child's developmental level(s) may affect the child's functional skills in activities of daily living
    - Results that are useful for developing intervention goals [D2]
34. It is recommended that all professionals involved in the assessment of a child with Down syndrome communicate with each other regarding their findings and recommendations. [D2]

Assessing Cognition

Cognition includes the process of the brain that allows us to experience the environment and to remember, think, act, and feel emotions (see Table 5, page 48). Cognitive processes are complex, diverse, and highly interrelated. The components of cognition that are particularly important with respect to Down syndrome include attention and exploration, learning and memory, and reasoning and problem solving.

Acquisition of specific cognitive skills in young children with Down syndrome appears to be similar in sequence to that of typically developing children, but the rate at which these skills are acquired is slower in children with Down syndrome. In general, when compared with typically developing children, children with Down syndrome have:

- A slower rate of cognitive development (cognitive development is delayed and new skills are learned more slowly)
- More difficulty generalizing skills (more difficulty applying what is learned in one setting to a new setting)
- Some qualitative differences in how cognitive skills are performed or integrated with other behaviors
- More difficulty with complex reasoning and judgment
- A lower final level of cognitive skills and abilities (Spiker 1997, Stray-Gunderson 1995)

As in the general population, there is a wide range of cognitive skills and abilities in children with Down syndrome. While they are likely always to be developmentally behind typically developing children of the same age, most

children with Down syndrome are able to learn and grow intellectually, especially when provided with learning opportunities and experiences that promote cognitive and social competence.

Table 5: Assessing Cognition in Young Children

Definition of Cognition: Cognition includes the processes of the brain that allow us to experience the environment and to remember, think, act, and feel emotions. Cognitive processes are complex, diverse, and highly interrelated.

Components of Cognition:

Arousal, orientation, attention, and executive function

- Arousal
- Orientation
- Perception
- Selective attention
- Sustained attention
- Exploration—stimulus
- Executive functions

Memory

- Visual processing
- Auditory processing
- Object permanence
- Person permanence
- Short- and long-term memory

Information processing function

- Discrimination
- Pattern recognition
- Imitation
- Generalization
- Cause-and-effect association
- Deducing rules for responding
- Cross-sensory information exchange
- Processing multiple sources of information simultaneously

Reasoning, concept formation, and problem solving

- Response flexibility
- Analogous reasoning
- Incidental learning
- Trial-and-error learning
- Creativity
- Symbolic play
- Perspective taking
- Social context and rules

How to Measure Cognition in Young Children:

- Standardized testing designed to arrive at a developmental quotient (DQ)
- Criterion-referenced and curriculum-based assessments
- Direct observation

Adapted from: New York State Department of Health, Clinical Practice Guidelines, Autism/Pervasive Developmental Disorders 1999

Measuring cognition

Several standardized tests have been developed to measure general cognitive abilities in young children. These tests are typically lists of tasks and specific questions administered by a professional. Testing procedures include direct testing of the child, observation of the child's behavior, and an interview with parents. Depending upon the standardized tests used, numerical measures of cognitive level are derived in various forms including:

- Developmental Quotient (DQ)
- Mental Development Index (MDI)
- Intelligence Quotient (IQ)
- Mental Age (MA)
- Age Equivalent (AE)

Scores on these tests are meant to reflect the child's performance compared with the performance of other children of the same chronologic age. Some tests generate mental age (MA) scores that are given in months. The mental age of a child is defined as the chronologic age at which an average person in the general population would make the same number of correct responses on the standardized test of cognitive ability. For children under 2 to 3 years of age, test results are given as DQ, MDI, or MA scores.

Stability and reliability of cognitive test scores at different ages

Results of these standardized tests of intelligence are not considered reliable or valid when given to children under 6 months old. For children ranging from 6 months to 3 years old, standardized scores of cognitive level (DQ, MDI, or MA) are considered valid, but test scores in this age range often vary over time even for typically developing children. Cognitive abilities for young children are generally inferred from the child's performance of other skills (such as motor and language), and tend to be more difficult to assess.

Recommendations (Assessing Cognition)

Importance of assessing cognition in children with Down syndrome

1. It is important to assess cognitive ability in children with Down syndrome because the child's cognitive ability:
    - Affects all other areas of development

- Helps determine the kinds of interventions that are most appropriate
- Provides a baseline for measuring progress

  [C_{dc}] (Berry 1984, Berry 1984A, Loveland 1987, Loveland 1987A)

Early Intervention Policy ❖ An assessment of cognitive development is a required component of the multidisciplinary evaluation.

Conducting the cognitive assessment

2. It is important to recognize that cognitive skills are an integral component of skill development in all the other developmental domains.

   [C_{dc}] (Berry 1984, Berry 1984A, Loveland 1987, Loveland 1987A, Mahoney 1981)

3. It is important to recognize that norm-referenced cognitive assessments are generally not considered a valid measure of cognitive function before approximately 6 months of age. [D1]

4. From age 0 to 12 months: It is recommended that a norm-referenced or curriculum-linked assessment be used. Examples include:
   - Battelle Developmental Inventory
   - Hawaii Early Learning Profile
   - Carolina Curriculum
   - Mullen Scales of Early Learning
   - Uzgiris-Hunt Scale [D1]

5. From age 1 to 3 years: It is recommended that standardized/norm-referenced tests be used to assess cognitive level. Examples include:
   - Bayley Scales of Infant Development II (BSID-II)
   - Leiter Performance Scale - Revised
   - Gessell Developmental Schedules [D1]

     [See Appendix C, Developmental Assessment Tests]

6. When evaluating the cognitive function of young children with Down syndrome, it is important to:
   - Conduct evaluations at “eye level” with the child
   - Provide appropriate postural supports for children who have not yet developed postural control

- Take into account fine and gross motor skills when methods are selected to assess cognitive status

  [C_{dc}] (Cobo-Lewis 1996, Haley 1986, Rast 1985)

7. It is important to adjust testing procedures (if appropriate) to accommodate the longer response time needed by children with Down syndrome.

   [C_{dc}] (Berry 1984, Bradley-Johnson 1981, Lewis 1982, Wishart 1987)

8. It is recommended that assessment of the child be done in the home or the child's other natural environments whenever possible. [D1]

Components of the cognitive assessment

9. It is important to include measurement of global cognitive skills, specific skills, and developmental milestones. [D2]

10. It is recommended that repetition of tasks be used in assessing learning aptitude and cognitive development in young children with Down syndrome.

    [C_{dc}] (Berry 1984, Berry 1984A, Wishart 1987)

11. When assessing cognitive development in young children with Down syndrome, it is important to include:
    - General information
    - Conceptual development
    - Memory
    - Attention
    - Problem-solving skills
    - Perceptual motor function
    - Functional motor skills
    - Receptive and expressive language
    - Adaptive behavior
    - Nonverbal and verbal measures
    - The child's ability to use skills and information in varied environments

    [C_{dc}] (Mahoney 1981, Mundy 1988)

12. It is important that assessment of cognition in young children with Down syndrome evaluate both the quantitative and qualitative aspects of a child's performance using:
    - Standardized and normed tests of cognitive development

- Curriculum-linked and norm-referenced assessments
- Observational tools and procedures
- Play-based assessments

  [C_{dc}] (Berry 1984, Krakow 1983, Lewis 1982, Loveland 1987, Loveland 1987A, MacTurk 1985, Wishart 1987)

Specific assessment approaches

13. It is recommended that the choice of tests (assessment instruments) used to assess the cognitive level of a child with Down syndrome be based on both the child's mental age (MA) and chronologic age (CA). It is important to recognize that this may involve the use of more than one test.

    [C_{dc}] (Berry 1984, Berry 1984A, Bradley-Johnson 1981, Dunst 1988, Krakow 1983, Lewis 1982, Loveland 1987, Loveland 1987A, MacTurk 1985, Ohr 1991, Ohr 1993, Wishart 1987)

14. It is recommended that assessment instruments be used that are based on both mental age (MA) and chronologic age (CA), but not necessarily in the same assessment session or test. [D2]

15. When assessing a child's nonverbal cognitive level, it is useful to observe:
    - The child during structured and free play
    - The child's interactions with people and objects in varied environments

      [C_{dc}] (Berry 1984, Krakow 1983, Kasari 1990)

16. When assessing exploratory behavior in young children with Down syndrome, it is important to:
    - Include opportunities for the child to manipulate objects, and to look at, mouth, and listen to different stimuli
    - Evaluate social exploratory behavior

      [C_{dc}] (Bradley-Johnson 1981, Kasari 1990, Krakow 1983, Landry 1989, Landry 1990, Lewis 1982, MacTurk 1985, Ruskin 1994)

17. When assessing learning style in young children with Down syndrome, it is important to:
    - Provide concrete directions
    - Include appropriate reinforcement for performance of specific skills
    - Allow for testing to be done over several sessions if needed (learning ability or aptitude may not be measured adequately in a single session or setting)

- Consider environmental influences, such as parent/caregiver teaching style

  [C_{dc}] (Berry 1984, Berry 1984A, Ohr 1991, Ohr 1993, Wishart 1987)

18. When assessing attention in young children with Down syndrome, it is important to:
    - Use motivating and interesting developmentally appropriate objects
    - Evaluate attending skills compared with those of other children of equivalent developmental and chronologic age
    - Allow for longer testing times than usual whenever possible

      [C_{dc}] (Bradley-Johnson 1981, Krakow 1983, Lewis 1982, Loveland 1987, Loveland 1987A, MacTurk 1985)

19. It is important to remember that when an evaluation is conducted once, it is not a test of mastery. Mastery is the ability to reproduce an activity over time in different situations with different material and with different people. [D2]

Use and interpretation of standardized cognitive tests

20. It is important to use standardized scores when reporting the results of a cognitive test. However, using age equivalents descriptively may also be helpful in explaining the scores to those not familiar with the standardized tests scores. [[D2]

21. When reporting and interpreting the results of standardized cognitive tests of children with Down syndrome, it is important that professionals understand the range of normal variation scores that is expected for a particular standardized test. (This is represented by the standard deviation of the normative test scores for that specific assessment tool.) [D2]

22. When interpreting results of standardized tests of cognition for young children with Down syndrome, it is important to recognize that:
    - Developmental quotients (DQs) typically appear to decline during the first two years of life for children with Down syndrome

- An apparent decline in DQ during the first two years in children with Down syndrome usually does not represent a true decline in cognitive functioning but rather is usually an artifact of the tests, since cognitive tests rely more on language items after 12 months of age and children with Down syndrome are particularly delayed in expressive language *[C_{dc}] (Carr 1970, Mahoney 1981, Mundy 1988)*

23. It is important to remember that when a child is young, performance on cognitive tests may fluctuate based on a variety of factors, and therefore the scores on these tests are often not stable. Hence, cognition may not be adequately measured in a single session or a single setting. [D2]

Assessing Communication

Communication is the process used to produce and comprehend messages, and to exchange information with others. The components of early communication that are particularly important with respect to Down syndrome include babbling, receptive and expressive language, language learning sequences, and nonverbal communication development (use of gestures).

The early vocal development of infants with Down syndrome and typically developing infants tends to be fairly similar. Differences begin to appear, however, by approximately 6 to 8 months of age when typically developing infants begin canonical babbling (babbling characterized by consonant-vowel syllables that are speech-like, such as “ba”). Infants with Down syndrome typically do not develop this type of babbling until approximately 9 to 10 months of age. Young children with Down syndrome typically exhibit a delay in overall language development, but particularly show a discrepancy between their receptive and expressive language. Receptive language is more likely to be commensurate with mental age (MA), while expressive language is usually more delayed. Young children with Down syndrome, particularly those at the single-word expressive level, tend to use gestures more than typically developing children.

Recommendations (Assessing Communication)

Importance of assessing communication in children with Down syndrome

Early Intervention Policy ❖ An assessment of communication development is a required component of the multidisciplinary evaluation.

1. It is important to assess communication adequately in children with Down syndrome because the child's ability to communicate has implications for:
   - Assessing cognition
   - Making intervention decisions
   - Providing a baseline for monitoring progress
   - Evaluating outcomes

   [C_{dc}] (Mahoney 1981, Mundy 1988)

Conducting the assessment

2. When assessing children who live in multilingual homes, it is important to conduct the assessment in the primary language of the child and the parents whenever possible. [D2]

Early Intervention Policy ❖ The multidisciplinary evaluation must be performed using nondiscriminatory procedures as defined in program regulations (see Appendix D) and be conducted in the child's dominant language whenever feasible.

3. When assessing communication in a young child with Down syndrome, it is important to:
   - Consider the interrelationship between cognitive development, motor development, and language milestones
   - Provide appropriate postural support for children who have compromised motor control/development
   - Consider the child's medical history (such as respiratory problems and history of otitis media with effusion [OME])
   - Assess intervention needs for communication as early as possible
   - Ensure that the testing environment is quiet and free of distractions in order to help the child maintain focus of attention on the tester and the tasks involved

   [C_{dc}] (Cobo-Lewis 1996, Haley 1986, Mahoney 1981, Mundy 1988, Rast 1985)

Table 6: Assessing Communication

Definition of Communication: Communication is the process used to produce and comprehend messages, and includes both verbal and nonverbal communication:

- **Verbal (oral) communication**--the use of spoken language or other verbal utterances to communicate.
- **Nonverbal communication**--all aspects of communication between the child and others except for spoken language. This may include the use of such things as facial expressions, pointing, and gesturing to communicate with others. In older children this may include the use of symbol systems.

Components of Verbal Language: Verbal language is the use of sounds, words, and phrases to communicate verbally between individuals. Verbal language includes:

- **Phonology**--the sound system of spoken language.
- **Morphology**--the system that describes the smallest meaningful units in language, such as the syllables used to form words.
- **Syntax**--the system of rules governing the order and combination of words to form phrases or sentences.
- **Semantics**--the system that governs the meaning of words and sentences.
- **Pragmatics**--the system that combines all other language components in functional use of language.

Types of Communication Disorders:

Communication disorders in young children can be classified as hearing disorders, language disorders, or speech disorders, as defined below:

- **Hearing disorders** involve impairment of the auditory system (the mechanical and neurological elements of the ear and brain involved with hearing). A hearing disorder may limit the development, comprehension, production, and/or maintenance of speech and/or language.
- **Language disorders** involve impaired comprehension and/or use of spoken, written, and/or other symbol systems. A language disorder may involve the following (in any combination):
  (1) the form of language (phonology, morphology, syntax)
  (2) the content of language (semantics), and/or
  (3) the functional use of language in communication (pragmatics)
- **Speech disorders** involve impairment of articulation of speech sounds, fluency, or voice. The three subcategories of speech disorders are:
  - *Articulation disorders*, the atypical production of speech sounds (such as problems with pronunciation)
  - *Fluency disorders*, an interruption in the flow of speech, including abnormal rate and rhythm, and unintentional repeating of sounds/syllables (stuttering)

Table 6: Assessing Communication

- *Voice disorders*, the abnormal production of vocal quality, pitch, loudness, or resonance

How to Measure Communication in Young Children

Methods to assess hearing disorders in young children
(also see Table 14, page 98):

- Evaluation of the hearing history
- Behavioral audiometry testing
- Electrophysiologic procedures

Methods to assess speech and language disorders include:

- Standardized testing designed to assess speech and language development
- Direct observation of the child's interactions, especially with parents, other children, or professionals
- Review of history of attainment of developmental milestones

Adapted from: American Speech-Language-Hearing Association 1993; and New York State Department of Health, Clinical Practice Guidelines, Communication Disorders 1999
(Continued from previous page)

4. Because parents often have the most detailed knowledge of the child's communication history, it is important to use parent report scales as well as formal evaluation procedures when assessing communication in a young child with Down syndrome.

   [C_{dc}] (Caselli 1998, Cobo-Lewis 1996, Lynch 1995)

Early Intervention Policy ❖ A parent interview must be included as part of the multidisciplinary evaluation. Families may also participate in an optional family assessment.

5. When assessing a young child with Down syndrome, it is important to evaluate the child's responses to persons and not just responses to objects. This is important because young children with Down syndrome tend to spend more time looking at people than at objects, compared to typically developing children of similar chronologic age.

   [C_{dc}] (Crown 1992, Gunn 1982, Kasari 1990)

6. There is a great deal of variability in early vocal development in young children with Down syndrome. It is important to assess the child over multiple sessions for an accurate assessment, as a one-time assessment may be misleading. It is also important to include observation and assessment of a child's communication skills in more than one setting.

   [C_{dc}] (Cobo-Lewis 1996, Franco 1995, Lynch 1995, Mundy 1988, Steffens 1992)

7. It is recommended that the family's need for various types of information and resources to support communication development (e.g., sign language) always be included as a part of the assessment of communication. [D2]

Components of the assessment of communication

8. It is recommended that a speech-language pathologist review the results of infant hearing screening and do a baseline communication assessment in the first three months. Components include:
   - Responses to sound
   - Oral-motor/feeding
   - Visual attention and tracking
   - Vocal quality (cry/pitch/volume) [D2]

9. It is recommended that a speech-language pathologist familiar with working with young children assess the child's communication development at least every 6 months in the first 3 years.

   [C_{dc}] (Caselli 1998)

10. In assessing communication in a young child with Down syndrome, it is important to consider the child's:
    - Cognitive level
    - Hearing and vision status
    - Respiratory function and breath support for vocalization
    - Motor development
    - Primary language as well as the child's other language environments

      [C_{dc}] (Carr 1970, Cobo-Lewis 1996, Mahoney 1981, Mundy 1988)

11. It is important that in-depth communication assessment for children with Down syndrome from age 6 months to 3 years include all of the following:
    - Standardized tests of receptive and expressive language, as appropriate
    - Language samples (verbal and nonverbal)

- Use of gestures and other nonverbal communication, including (but not limited to) augmentative systems and sign language
- Hearing assessment, including an audiologic evaluation by an audiologist
- Oral-motor/speech-motor assessment
- Parent report [D2]

12. It is recommended that all assessment tools encompass a wide range of skill levels so that the score is not influenced by floor or ceiling effects (i.e., the test should not be so easy that the child performs 100 percent of the tasks [ceiling effect], nor so hard that all the scores are close to zero percent [floor effect]). [D2]

Communication developmental milestones

13. It is important to consider the child's developmental milestone progress relative to both children with Down syndrome and typically developing children. When assessing developmental milestones, it is important to recognize that children will vary as to when specific developmental milestones are attained.

[C_{dc}] (Caselli 1998, Cobo-Lewis 1996, Harris 1983, Lynch 1995, Steffens 1992)

Table 7: Communication/Language Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
Milestone	**Average**	**Range**	**Average**	**Range**
Reacts to sounds	1	.5 - 1.5	.5	0 - 1
Turns to sound of voice	7	4 - 8	4	2 - 6
Canonical babbling	11	7 - 18	8	5 - 14
Responds to familiar words	13	10 - 18	8	5 - 14
Responds to simple instructions	16	12 - 24	10	6 - 14
Jabbers expressively	18	12 - 30	12	9 - 18
Words other than "Mama"/"Dada"	18	13 - 36	14	10 - 23
Indicates desires with gestures	22	14 - 30	14.5	11 - 19
Combines 2-word phrases	30	18 - 60+	18	16 - 24
Uses words to communicate	1.5 - 6 yrs			

Adapted from: Cunningham 1996

Audiologic assessment (hearing)

14. It is recommended that all newborn infants with Down syndrome have their hearing screened prior to discharge from the hospital. [D2]

> ***New York State Note:*** *Under NYS public health law, newborn hearing screening is now required for all newborn infants.*

15. It is recommended that an audiologist and speech-language pathologist be involved in monitoring the development of auditory behaviors and progression of auditory skills for young children with Down syndrome. [D2]

16. It is recommended that all children with Down syndrome have ongoing monitoring and periodic testing of their hearing by an audiologist. This is important for young children with Down syndrome because:
    - Hearing is a key component of oral language development
    - There is a high incidence of conductive hearing loss that may result from the increased incidence of otitis media with effusion (OME)
    - It is difficult to detect a mild hearing loss by observation
    - Early diagnosis of hearing loss and appropriate intervention may improve outcomes [D2]

17. When hearing loss is suspected in a young child, it is recommended that the type, degree, and configuration of a child's hearing loss be determined as soon as possible, as this influences intervention strategies. [D2]

> **Early Intervention Policy** ❖ Audiological services are an early intervention service. An audiological evaluation can be performed as a supplemental evaluation, as part of the multidisciplinary evaluation process, or when identified as an area of need and included in the Individualized Family Service Plan.

Specific assessment approaches

18. It is important to include the following when assessing communication development in young children with Down syndrome:
    - Use of canonical babbling (babbling characterized by consonant-vowel syllables that are repeated, e.g., "baba," "nana")
    - Use of social referencing

- Ability to use nonverbal communication strategies, such as pointing to request or to show an item, including:
- Facility of use of gestures
- Nonverbal receptive-expressive language
- Functional use of spoken language (how children use words and sounds to get what they want)

  [C_{dc}] (Caselli 1998, Cobo-Lewis 1996, Franco 1995, Kasari 1990, Kasari 1995, Lynch 1995, Mundy 1988, Steffens 1992)

19. In children with Down syndrome, mean length of utterance (MLU) may not be an accurate predictor of other language abilities. It is important that assessment of communication in young children with Down syndrome not be limited to evaluation of MLU.

    [C_{dc}] (Harris 1983)

20. Strategies recommended for assessing communication in young children with Down syndrome include:
    - Collecting recorded language samples as a component of each assessment
    - Use of both structured and unstructured language evaluation tools (language samples)
    - Consideration of operant procedures as an approach for testing receptive language

      [C_{dc}] (Caselli 1998, Harris 1983, Lynch 1995, Steffens 1992)

21. It is important to include norm-referenced or standardized tests when assessing communication development in young children with Down syndrome. Examples include:
    - The MacArthur Communicative Development Inventory (an inventory of vocabulary development obtained through parent report, and reviewed in the NYSDOH Clinical Practice Guideline for Communication Disorders)
    - The McCarthy Scales of Development (a screening tool that can be used as part of the assessment of communication development for children who have a mental age [MA] of 24 months or older)
    - The Rosetti Infant Toddler Language Scale (a criterion-referenced test that assesses preverbal and verbal communication development)

      [C_{dc}] (Caselli 1998, Mahoney 1981)

Use of alternative and assistive communication devices

Early Intervention Policy ❖ Assistive technology devices and services are included as early intervention services. Augmentative communication systems are considered "assistive technology devices." The potential need for an augmentative communication system could be identified through the child's initial multidisciplinary evaluation, or later through a supplemental evaluation or ongoing assessment. The need for assistive technology devices must be agreed upon by the parent and the Early Intervention Official, and be included in the Individualized Family Service Plan (IFSP).

22. When assessing the emergence of language in young children with Down syndrome, it is important to consider the need for transitional language systems and augmentative communication (for example, assistive listening devices and FM systems). [D1]

23. It is important to consider the child's motor skills as well as cognitive/receptive language skills when assessing appropriate forms of alternative communication. [D1]

Assessing Social Interactions and Relationships

The social domain refers to the ability to interact and relate to other people, including parents and peers. The components of social development that are particularly important with respect to young children with Down syndrome include social attention, social interactions (particularly with the mother), attachment, and play.

In general, some aspects of social development in young children with Down syndrome appear to be similar to the social development of typically developing children of the same mental age. For example, the social attention of young infants with Down syndrome appears to develop in a similar progression as typically developing infants but at a slower rate. However, social interactions with young children with Down syndrome may be more difficult to elicit and interpret than interactions with typically developing children.

Compared with typically developing children, young children with Down syndrome tend to take less initiative in social interactions. Young children with Down syndrome tend to initiate and respond to interactions in a less contingent and predictable manner than do typically developing children, and their social and communicative signals are less readable to others. At play, young children

with Down syndrome tend to have more limited repertoires than do typically developing children, and they tend to change the focus of their play more often.

Recommendations (Assessing Social Interactions and Relationships)

Importance of assessing social interactions and relationships

1. It is important to assess social interactions and relationships in children with Down syndrome because of the potential impact on intervention decisions. [D2]

Early Intervention Policy ❖ An assessment of social/emotional development is a required component of the multidisciplinary evaluation.

Conducting the assessment

2. When assessing social development, it is important to consider the child's:
   - Cognitive skills
   - Receptive and expressive language skills
   - Hearing status
   - Gross and fine motor skills

   [C_{dc}] (Bressanutti 1992, Cielinski 1995, Kasari 1990, Kasari 1995, Knieps 1994, Landry 1989, Landry 1990, Ruskin 1994)

3. It is important to remember that the child's behavior may vary in response to the environment/setting and other factors (health, hunger, time of day, familiarity and comfort with the evaluator). Time, place and other child-specific factors are important when planning for assessments and when considering the results of the assessment. To the extent it is reasonable, it is recommended that the child be assessed in multiple sessions and in a variety of different environments relevant to the child's daily life. [D2]

4. It is important to consider the developmental characteristic of young children with Down syndrome and to take this into account when assessing social development. For example, young children with Down syndrome tend to:
   - Pay more attention to persons than to objects
   - Have lower levels of sustained engagement/attention

- Be more responsive to directive than to suggestive requests
- Need sufficient time to respond when having their attention redirected
- Respond better when visual stimuli are provided at an eye-gaze level appropriate for facilitating performance

  [C_{dc}] (Crown 1992, Gunn 1982, Kasari 1990, Kasari 1995, Landry 1989, Landry 1990, Landry 1994, Ruskin 1994)

5. Because young children with Down syndrome tend to have lower levels of sustained engagement/attention, it may be useful to administer the assessment over shorter periods rather than one long session (for example, two 20-minute sessions instead of one 40-minute session).

   [C_{dc}] (Cielinski 1995, Landry 1989)

Components of the assessment of social interactions and relationships

6. Assessment of social interactions and relationships includes evaluation of:
   - Social initiation (showing or giving objects to others for social purposes)
   - Social imitation (imitating actions of others)
   - Age-expected reciprocity (turn-taking during play)
   - The child's attachment behavior patterns in the presence of a caregiver (neutrality, excessive clinging, or avoidance of parent/caregiver)
   - Social interactions with familiar as well as unfamiliar adults and peers
   - The child's ability to make transitions from one play activity/toy to another
   - Joint attention (shared interest in object or activity) [D2]
7. When assessing the social development of young children with Down syndrome, it is important to include direct observation of the child's interactions with others (parents, caregivers, siblings, other children, service providers), as well as information from the child's parent and/or primary caregiver. [D2]

Early Intervention Policy ❖ A parent interview must be included as part of the multidisciplinary evaluation.

8. As with all other areas of development, the child's environment, especially the home and family environment, can play a significant role in the child's social development. When assessing social development, it is important to consider:
   - The cultural values and the social rules or customs of the family that may influence social development or the acquisition of social skills
   - The child's home and other environments with regard to opportunities for nurturing, stimulation, and learning, or lack thereof
   - Any significant family history factors that may affect the child's development of social skills
   - The impact of the family's (immediate and extended) emotional response to having a child with Down syndrome [D2]

Specific assessment approaches

9. It is important to remember that since children with Down syndrome have a tendency to focus on faces rather than objects, it may be useful to:
   - Use facial stimuli to direct the child's attention appropriately
   - Use a facial expression scale to assess affective expressions
   - Use positive reinforcement when the child appropriately pays attention to toys and testing materials rather than to parents/tester

   [C_{dc}] (Crown 1992, Gunn 1982, Kasari 1990, Kasari 1995, Landry 1990)

10. Since children with Down syndrome have a tendency to change the focus of their play/activities more often than other children, it may be helpful to:
    - Be flexible in response to the child's lead (unless the standardized test requires a specific order)
    - Use music and singing to increase attention skills

    [C_{dc}] (Landry 1989, Landry 1990, Ruskin 1994)

11. When assessing social referencing and joint attention in children with Down syndrome, it is important to consider both verbal behaviors and nonverbal behaviors (facial, gestures, body language, gazing).

    [C_{dc}] (Crown 1992, Gunn 1982, Kasari 1990, Kasari 1995, Knieps 1994, Landry 1989, Landry 1990, Ruskin 1994)

12. It may be useful to videotape children in typical situations as a method to obtain and preserve baseline behavior and to measure change over time, including:

- Parent-child interactions in play situations
- Parents' child-directed speech
- Parents' style of verbal interaction with regard to directiveness
- Sibling interactions
- Peer interactions in day care and other early childhood settings

  [C_{dc}] (Bressanutti 1992, Carvajal 1997, Cielinski 1995, Knieps 1994, Landry 1994, Mahoney 1990, Tannock 1988)

13. It is important to consider the child's level of hypotonicity and motor ability when assessing frequency of smiling. [D2]

14. When assessing atypical social development, it is important to compare children with Down syndrome to other children with Down syndrome. [D2]

Social developmental milestones

15. It is important to consider the child's developmental milestone progress relative to both children with Down syndrome and typically developing children. When assessing developmental milestones, it is important to recognize that children will vary as to when specific developmental milestones are attained. [D2]

Table 8: Social Development Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
Social/Self-Help Activities	**Average**	**Range**	**Average**	**Range**
Smiles responsively	2	1.5 - 4	1	1 - 2
Smiles spontaneously	3	2 - 6	2	1.5 - 5
Recognizes mother/father	3.5	3 - 6	2	1 - 5
Takes solids well	8	5 - 18	5	4 - 12
Feeds self crackers	10	6 - 14	7	4 - 10
Plays peek-a-boo/pat-a-cake	11	9 - 16	8	5 - 13
Drinks from cup	20	12 - 30	12	9 - 17
Uses spoon or fork	20	12 - 36	13	8 - 20
Feeds self fully	30	20 - 48	24	18 - 36
Undresses	38	24 - 60+	30	20 - 40

Table 8: Social Development Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
Social/Self-Help Activities	Average	Range	Average	Range
Plays social/interacting games	3.5 - 4.5 yrs.			
Uses toilet/potty without help	4 - 5 yrs.			

Adapted from: Cunningham 1996
(Continued from previous page)

Assessing Motor Development

Motor function is the process of sitting, standing, moving in space or place, and using our hands to play, care for ourselves, and work. Motor abilities are the skills that allow us to manipulate, move around in, and explore the world. Motor development depends on how sensory input is processed in the brain to result in a purposeful movement. The components of motor development that are particularly important with respect to Down syndrome include postural control, reflexes and reactions, gross and fine motor movements, and sensory processing.

Young children with Down syndrome tend to experience general developmental motor delays. Gross and fine motor developmental milestones are achieved at a slower rate than among typically developing children. Young children with Down syndrome tend to experience hypotonia (low muscle tone), hyperflexibility, and delays in the emergence and fading of reflexes and automatic patterns of movement. Generally, the delay in motor skills is less noticeable during the first 6 months, although there are often delays in antigravity movements and postural control that result in development of compensatory and atypical movement strategies.

Hands of children with Down syndrome tend to differ from typically developing children in size, age of calcification, hypomobility of joints, low muscle tone, and possibly thumb position. This can affect strength of grasp, development of arches of the hands, grasp patterns, and dexterity.

It has been suggested that children with Down syndrome have difficulty integrating kinesthetic (joint), vestibular (movement), and auditory input, and that they have a greater dependence on visual feedback than do typically

developing children. This may result in a longer motor response time needed by children with Down syndrome.

Assessment of motor development includes assessment of control of movement and posture, tone, and strength. Gross motor development refers to the ability to move the large muscle groups of the body (neck, trunk, and limbs), while fine motor development generally refers to the use of the hands and fingers.

Recommendations (Assessing Motor Development)

Importance of assessing motor development

1. When assessing young children with Down syndrome, it is important to assess their motor development and functioning because of the potential impact on intervention decisions and implications for outcomes. [D2]

Early Intervention Policy ❖ An assessment of physical development, including motor development, is a required component of the multidisciplinary evaluation.

Conducting the motor assessment

2. Because children with Down syndrome often have underlying serious health conditions (such as congenital heart disease and respiratory problems), it is important to obtain appropriate medical clearance before initiating a motor assessment. [D2]

3. When assessing motor development in young children with Down syndrome (and when caring for young children with Down syndrome), avoid rapid rotary or bouncing movements that may cause extreme flexion or extension movements of the neck because of the risk for complications due to possible atlantoaxial subluxation. (This is a looseness of the ligaments of the first two cervical (neck) vertebrae. About 15 percent of children with Down syndrome have x-ray evidence of atlantoaxial subluxation.) [D2]

4. It is important to consider that environmental stimulation may affect motor responses during the assessment. For example, verbal, visual, and tactile stimulation may affect movement frequency. [D2]

5. Children with Down syndrome may require more intense kinesthetic and proprioceptive stimulation than do typically developing children to elicit a

response. Additionally, there may be a longer lag time between the stimuli and the response in children with Down syndrome than in typically developing children.

[C_{dc}] (Ulrich 1995, Ulrich 1997)

Components of the assessment of motor development

6. It is important to consider the following when assessing motor development and functioning in young children with Down syndrome:
   - The interrelationship between the child's cognitive development and motor development
   - The child's receptive language skills
   - The child's overall health status and neurologic function
   - The degree of any cardiac and respiratory distress or compromise
   - Oral-motor function and needs
   - The need for head, trunk, or lower extremity supports
   - The need for appropriate adaptive equipment and/or the need to adapt the home environment
   - The need for parent training/support to enhance motor development

   [C_{dc}] (Haley 1986, Haley 1987, Rast 1985)

7. In children with Down syndrome, it is recommended that assessment of gross motor skills begin by 3 months of age, and assessment of fine motor skills begin by 6 months of age (see Table 9, page 71).

   [C_{dc}] (Cobo-Lewis 1996, Rast 1985)

8. When assessing motor function in young children with Down syndrome, it is important to include observations of variability and complexity of movement patterns because earlier development of complex movements (such as kicking) is related to earlier walking.

   [C_{dc}] (Ulrich 1995)

9. It is important to assess breathing patterns in both quiet and active states for evidence of respiratory distress (such as increased respiratory rate, nasal flaring, chest retractions, diaphragmatic breathing, or use of accessory muscles). It is particularly important to assess breathing patterns and respiratory status in children with Down syndrome because:
   - Children with Down syndrome tend to have decreased muscle tone, which can lead to decreased pulmonary function

- The increased work of breathing makes it more difficult to feed orally, and for infants to coordinate sucking, swallowing and breathing
- Respiratory support is important for vocalization [D2]

10. It is important to assess the need for foot and ankle support when children with Down syndrome begin standing to ensure appropriate foot alignment. Examples of commonly used orthotic devices that help support the ankle and foot include:
    - Submalleolar orthoses (UCBL)
    - Supramalleolar orthoses (SMO)
    - Ankle foot orthoses (AFO)
    - Knee ankle foot orthoses (KAFO) [D2]
11. It is important to continually assess the need for ongoing orthotic support and to modify use of orthotic supports as appropriate. [D2]

Table 9: Components of a Motor Assessment

Motor Attributes to be Assessed for All Ages

- Reflexes, postural reactions, protective reactions
- Postural control
- Postural alignment and symmetry
- Muscle tone
- Muscle strength
- Range of motion and joint laxity
- Pulmonary function
- Variety and complexity of movements
- Visual attention and tracking
- Sensory responsiveness to movement and touch

Activities Observed and Components Assessed

Birth to 6 months:

Movements and postural control

- Supine/Prone
- Side-lying
- Supported sitting
- Supported standing
- Grasp
- Hand-to-mouth movements
- Scapula (shoulder) stability

Oral movement for sucking, feeding, and sound production

6 to 12 months:

Sitting

- Postural control
- Base of support
- Ability to use hands

Table 9: Components of a Motor Assessment

Mobility and exploration of environment

- Rolling
- Prone progression
- Belly crawling
- Digital (finger) grasp
- Transfers objects hand to hand
- Reaching patterns

Oral movements for eating, drinking, and sound production

12 to 24 months:

Sitting

- Postural control
- Moving in and out of sitting
- Base of support/use of hands
- Variety of postures

Mobility and exploration of environment

- Creeping, crawling, climbing
- Pulling to stand
- Standing
- Cruising
- Taking steps independently
- Release of objects
- Eye-hand coordination
- Refinement of grasp patterns
- Self-feeding

24 to 36 months:

Ability to negotiate in the environment independently

Walking on level, unlevel, and uneven surfaces

Stair climbing

Climbing on playground equipment

Use of coloring/drawing and writing utensils

(Continued from previous page)

Specific assessment approaches

12. It is important that the assessment of motor function not be limited to an evaluation of the child's progress in attaining motor milestones. When assessing motor development in young children with Down syndrome, it is also very important to obtain an adequate assessment of the *quality* of movements.

    [C_{dc}] (Haley 1986, Haley 1987, Rast 1985)

13. When assessing motor function in young children with Down syndrome, it is important to focus on postural reactions and their development. Focusing

only on motor milestones while neglecting postural reactions (such as head righting) may give a false impression that motor development is progressing normally in young infants with Down syndrome. It is important to include assessment of:

- Compensatory movement strategies that may be interfering with future motor development. For example, children might use protective reactions to compensate for undeveloped postural control, or they might use neck hyperextension rather than active head control
- The impact of muscle tone and joint laxity on the child's posture and motor control

  [C_{dc}] (Haley 1986, Haley 1987, Rast 1985)

14. In assessing a child's motor development, it may be useful to make some changes in the environment in order to maximize motor output (such as increasing or decreasing auditory and visual stimuli that may distract from or enhance motor activity).

    [C_{dc}] (Ulrich 1995)

Tests of motor function

15. The use of standardized or norm-referenced developmental motor assessment tests may be useful when assessing motor function in young children with Down syndrome. Commonly used developmental motor assessment tests are listed in Table 10, page 74 (also see Appendix C).

    [C_{dc}] (Cobo-Lewis 1996, Haley 1986, Haley 1987, Rast 1985)

Motor developmental milestones

16. It is important to consider the child's developmental milestone progress relative to both children with Down syndrome and typically developing children. When assessing developmental milestones, it is important to recognize that children will vary as to when specific developmental milestones are attained (see Table 11, page 75). [D2]

Table 10: Developmental Motor Assessment Tests

Alberta Infant Motor Scale (AIMS)
Birth to 18 mos.
Postural control in supine, prone, sitting, standing

Battelle Developmental Inventory (BDI)
Birth to 8 yrs.
Social, adaptive, motor, communication, cognition

Bayley Scales of Infant Development II (BSID-II) (Second Edition)
Birth to 42 mos.
Cognitive, motor, behavior

Functional Independence Measure for Children (WeeFIM)
6 mos. to 7 yrs.
Mobility, self-care, communication, social, cognition

Gesell Developmental Schedules (GDS) - Revised
Birth to 72 mos.
Gross and fine motor, language, personal-social, adaptive

Hawaii Early Learning Profile (HELP)
Birth to 36 mos.
Cognition, language, gross and fine motor, social, self-help

Peabody Developmental Motor Scales (PDMS)
Birth to 7 yrs.
Reflexes, gross motor, fine motor

Pediatric Evaluation of Disability Inventory (PEDI)
6 mos. to 7½ yrs.
Self-care, mobility, social function

Test of Sensory Functions in Infants (TSFI)
4 mos. to 18 mos.
Tactile, deep pressure, visual-tactile integration, adaptive motor, ocular-motor, reactivity to vestibular stimulation

Toddler and Infant Motor Evaluation (TIME)
Birth to 42 mos.
Neurological function, stability, mobility, motor organization

Table 11: Motor Development Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
Milestone	**Average**	**Range**	**Average**	**Range**
Gross Motor				
Holds head steady/balanced	5	3 - 9	3	1 - 4
Rolls over	8	4 - 12	5	2 - 10
Sits without support (1 minute or more)	9	6 - 16	7	5 - 9
Pulls self to stand using furniture	15	8 - 26	8	7 - 12
Walks with support	16	6 - 30	10	7 - 12
Stands unassisted	18	12 - 38	11	9 - 16
Walks unassisted	23	13 - 48	12	9 - 17
Walks up steps with help	30	20 - 48	17	12 - 24
Walks down stairs with help	36	24 - 60+	17	13 - 24
Runs	about 4 yrs.			
Fine Motor/Adaptive				
Follows object with eyes, in circle	3	1.5 - 6	1.5	1-3
Grasps dangled ring	6	4 - 11	4	2 - 6
Passes object hand to hand	8	6 - 12	5.5	4 - 8
Pulls string to obtain toy	11.5	7 - 17	7	5 - 10
Finds toy hidden under cloth	13	9 - 21	8	6 - 12
Puts 3+ objects into a cup	19	12 - 34	12	9 - 18
Builds a tower of 2-inch cubes	20	14 - 32	14	10 - 19
Does simple 3-shape puzzle	33	20 - 48	22	16 - 30+
Copies a circle	48	36 - 60+	30	24 - 40
Matches shapes with colors	4-5 yrs.			

Adapted from: Cunningham 1982, Cunningham 1996

Assessing Adaptive/Self-Help Skills

Learning adaptive or self-help/self-care skills (sometimes also called functional skills) is usually one of the most important aspects of a child's development for parents of young children with Down syndrome. Adaptive self-help skills include dressing, grooming (bathing), feeding, and toileting. Mastering these functional skills allows the child to be more independent.

Adaptive self-help skills for children are behaviors that:

- Are immediately useful
- Enable a child to be more independent
- Allow a child to learn more complex skills
- Allow a child to live in a less restrictive environment
- Enable a child to be cared for more easily by family and others (Wolery 1989)

Young children with Down syndrome develop individual adaptive self-help skills in a progression similar to typically developing children, but they tend to develop these skills later than do typically developing children. These delays in developing self-help skills are probably related to delays in other domains, such as cognitive and motor.

Factors that may contribute to delays in development of adaptive or self-help skills for children with Down syndrome include:

- Cognitive delays (remembering steps, problem solving)
- Attentional difficulties (ability to focus on learning and completing tasks)
- Deficits in body awareness (awareness of position of body parts)
- Delays in motor skill development (postural stability, fine motor dexterity)
- Motor planning deficits (planning the movements needed to complete an unfamiliar motor task)

Recommendations (Assessing Adaptive/Self-Help Skills)

Importance of assessing adaptive/self-help skills

1. When assessing young children with Down syndrome, it is important to assess their adaptive or self-help skills as a measure of general functioning because of the potential impact on intervention decisions. [D2]

Early Intervention Policy ❖ An assessment of adaptive development is a required component of the multidisciplinary evaluation

2. As with all other areas of development, the child's environment, especially the home and family environment, can play a significant role in the development of the child's adaptive or self-help skills. Therefore, when assessing a child's adaptive/self-help skills, it is important to consider:
   - The cultural values and the social rules or customs of the family that may influence social development or the acquisition of adaptive or self-help skills
   - The child's home and other environments with regard to opportunities for nurturing, stimulation, and learning, or lack thereof
   - Any significant family history factors that may affect the child's development of adaptive or self-help skills
   - The emotional responses of the immediate and extended family to the birth of a child with Down syndrome and how these family responses may have an impact on the child's development [D2]
3. A developmental level for self-help skills can be completed by caregiver report. However, direct observation of the tasks is recommended in order to identify factors that may be contributing to the delay and to plan for appropriate intervention. [D2]
4. It is important to remember that children may demonstrate different abilities in different settings. In an unfamiliar setting, environmental and situational cues may be lacking, making the task more challenging for the child. [D2]

Adaptive/self-help developmental milestones

5. It is important to consider the child's developmental milestone progress relative to both children with Down syndrome and typically developing children. When assessing developmental milestones, it is important to recognize that children will vary as to when specific developmental milestones are attained. [D2]

Table 12: Self-Help Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
	Average	Range	Average	Range
Takes pureed solids well	8	5 - 18	7	4 - 12
Drinks from a cup	20	12 - 30	12	8 - 17
Uses fork or spoon	20	12 - 36	13	8 - 20
Undresses	38	24 - 60+	30	20 - 40
Feeds self fully	30	20 - 48	24	18 - 36
Urine control during day	36	18 - 50+	24	14 - 36
Bowel control	36	20 - 60+	24	16 - 48
Dresses self partially (not fasteners)	4 - 5 yrs.			
Uses toilet or potty without help	4 - 5 yrs.			

Adapted from: Cunningham 1996

Assessing Temperament and Behavior

The characteristic manner in which individuals engage their world is typically referred to as *temperament*. Individuals with Down syndrome are commonly stereotyped as easy in temperament, affectionate, and obstinate. However, this is not supported by research. Children with Down syndrome have individual personalities and can experience a wide range of feelings and emotional reactions.

In general, children with Down syndrome may be inherently less reactive to stimulations affecting their interactive capacities and responsivity. Therefore, they may appear more passive than other children of similar chronologic age. Some behaviors, which might be interpreted as an aspect of the child's temperament, may be the result of factors related to other aspects of the child's development. For example, young children with Down syndrome often understand more language than they are able to express; therefore, they may exhibit frustration during the communication process.

Recommendations (Assessing Temperament and Behavior)

General approach

1. It is important to assess the behavior and temperament of each child individually since children with Down syndrome vary in terms of these factors.

   [C_{dc}] (Marcovitch 1986, Marcovitch 1987)

2. It is important to consider health status (such as vision, hearing, and cardiac/respiratory conditions) in assessing behavior and temperament. [D2]

Working with the family

3. It is recommended that the parent report component of the temperament assessment be based on reports from both parents when possible. [D2]

4. When considering the results of the temperament assessment, it is important to remember that the parent's global report may be different from the results on a standardized scale. Parents may report that their children are easy but rate them as more difficult on a formal scale (although most scales have taken this into account in their scoring structure).

   [C_{dc}] (Marcovitch 1986, Marcovitch 1987)

Components of the assessment of behavior and temperament

5. In assessing a child with Down syndrome, it is important to identify behavior patterns, relative strengths, and problem areas, including:
   - Play skills (independent play and interactive play with parents, other adults, or other children)
   - Unusual responses to sensory experiences
   - Mood patterns
   - Activity and behavior patterns
   - Problem behaviors

     [C_{dc}] (Bridges 1982, Gunn 1985, Huntington 1987, Marcovitch 1986, Marcovitch 1987, Rothbart 1983, Vaughn 1994)

Specific approaches

6. The use of standardized or norm-referenced tests or scales may be helpful in assessing individual temperament/characteristics of children and may also

be useful in identifying the need for parenting supports/counseling. For example:

- Toddler Temperament Scale
- Infant Behavior Questionnaire

  [C_{dc}] (Bridges 1982, Gunn 1985, Huntington 1987, Marcovitch 1986, Marcovitch 1987, Rothbart 1983, Vaughn 1994)

ASSESSING THE RESOURCES, PRIORITIES, AND CONCERNS OF THE FAMILY

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

A family assessment of strengths and needs is an important component of planning interventions that will benefit the child and family. Intervention services are most effective if they are matched to the resources, priorities, and concerns of the family as well as the child. This is important because the needs of the family may be more predictive of outcome than are the child's needs, both for parent-related outcomes and child outcomes.

There are three essential family interaction patterns relevant to all children and families regardless of a child's disability or risk status (Guralnick 1997). These patterns include:

- The characteristics of the parent-child interaction (for example, encouraging, affectively warm, nonintrusive, appropriately structured, discourse-based, and developmentally sensitive patterns of caregiver-child interactions).
- The extent to which the family provides the child with diverse and appropriate experiences with the surrounding cultural, social, and physical environment (for example, the frequency and quality of contacts with different adults, the variety of toys and materials available, and the stimulation value of the general environment).
- The extent to which the family ensures the child's health and safety (for example, obtaining immunizations and regular routine/specialized health care, and providing adequate nutrition).

For a child with established disabilities, there are a variety of factors (stressors) that may interfere with a family's ability to establish patterns of interaction that optimally facilitate and support the child's development. Factors may include:

- Lack of information about the child's health and development
- Interpersonal and family stress
- Lack of resources or support
- Language or cultural considerations
- Threats to confidence in parenting skills

The extent to which these factors actually affect the family patterns depend on the magnitude of the stressors as well as the characteristics of the family. Not all families are the same. Important family characteristics include:

- Available supports (e.g., social support networks)
- Financial resources
- Interpersonal and problem-solving skills of the parents
- History of family parenting practices

A recent study found that for mothers of children with developmental disabilities, family characteristics (family cohesion, income, and level of family support) were more predictive of parenting and child-related stress than were child characteristics (Warfield 1999).

In a recent study of adaptive development in young children with Down syndrome, growth trajectories in communication, daily living, and social skills were predicted by measures of family processes (family cohesiveness and mother-child interactive behaviors) over and above that predicted by maternal education, whereas psychomotor measures during infancy did not predict development in adaptive domains (Hauser-Cram 1999).

A review of six studies (Knussen 1992) suggests that adequate "coping resources," including social support, can reduce the impact of potential stressors on families. In addition, those with adequate coping resources are less likely to appraise a potential stressor as "stressful." This research suggests that the most important social support is the existence of a confiding relationship, or strong ties, usually within the family.

A study designed to examine not only social support but the effects of loss of expected support and of the experience of nonsupportive behaviors suggests the

possibility that "nonsupport might be more than the loss of a protective factor and might actually become a risk factor" (Patterson 1997). Among the behaviors reported most often as nonsupportive are the following:

- Comparisons with other children
- Focusing only on what is wrong
- Questions concerning why a child cannot achieve developmental milestones
- Offering unsolicited and inappropriate advice
- Blaming parents for the cause of the condition
- Criticizing parental caregiving
- Pitying remarks concerning the child or the parents

The family assessment

Components of a family assessment include an assessment of the different categories of family strengths and needs. The approaches proposed for conducting a family assessment are generally not patterned after typical child assessment strategies focusing on administration of standardized tests. Methods for a family assessment may include:

- Informal discussions with families, using sensitive and focused interviewing techniques
- Assessment tools to help families identify, clarify, and communicate their goals and needs

Families will respond differently to the opportunity for a family assessment. Some parents will find it helpful to discuss their feelings, and others may find it intrusive. Some families may be uncomfortable with participating in a family assessment because they may interpret this assessment as a message that something is "wrong" with their family functioning, or because they may have had a previous negative experience during the assessment of their child.

Often professional assessments of family needs are weakly correlated with parents' assessments of needs. In family-oriented assessment, the task for professionals is to help parents to articulate the family's needs and goals in ways that are sensitive and objective (Krauss 1997).

Recommendations (Assessing the Resources, Priorities, and Concerns of the Family)

Importance of assessing the strengths and needs of the family

1. It is recommended that the family of a young child with Down syndrome be encouraged to participate in a family assessment process to help identify the resources, priorities, and concerns of the family. This is important because different families have different needs and the information gathered through this process can assist in planning the most effective intervention strategies and goals/objectives. [D2]

Early Intervention Policy ❖ Families must be offered the opportunity to participate in a family assessment as part of their child's multidisciplinary evaluation. The family assessment is voluntary to families. The evaluation team must use appropriately trained qualified personnel when conducting a family assessment.

Components of a family assessment

2. It is recommended that assessment of the resources, priorities, and concerns of the family include observation and/or discussion of factors such as:
   - The family's knowledge and need for information about Down syndrome
   - Family composition (including siblings and extended family)
   - Family demographics, education, and specific circumstances
   - Family values and culture
   - The family's current support systems and resources (including extended family and their attitudes)
   - The family's stressors, tolerance for stress, and coping mechanisms and styles
   - Family interaction and patterns of parenting style
   - Caregiving skills and sharing of caregiving responsibilities [D2]

Family assessment approaches

3. It is important to recognize that the family's resources, priorities, and concerns may change over time. Some families may require more frequent family assessments than do other families. It is recommended that there be

ongoing family assessment based on the individual needs of the family. [D2]

4. Family assessment involves respecting differences in family styles and goals. It is important that professionals conducting family assessments:
   - Develop a collaborative relationship with parents involving mutual respect
   - Listen to parents nonjudgmentally
   - Value and be interested in parents' input [D2]

Early Intervention Policy ❖ The multidisciplinary evaluation must be performed in the dominant language of the child whenever it is feasible to do so.

5. It may be useful to use a specific measurement tool, such as the Parenting Stress Index, to measure parental stress that may impact family well-being and child functioning. Important areas to address include:
   - Available social supports and resources
   - Family structure
   - Interpersonal and problem-solving skills of the parents
   - Parenting practices [D2]
6. Because some families may be uncomfortable with participating in a family assessment, it is important for professionals to:
   - Maintain confidentiality
   - Provide an appropriate setting and sufficient time to allow the family to express its needs and concerns
   - Respect differences in family styles and goals
   - Respect cultural differences
   - Avoid tendencies to judge the adequacy of any particular family [D2]
7. It is recommended that information gathered in the family assessment be used to help families:
   - Establish and articulate needs
   - Develop realistic priorities
   - Become aware of available services for the child and sources of social supports for the family, both formal and informal

- Obtain specific information about expected developmental patterns, progress of educational and therapeutic interventions, and any special problems likely to be encountered [D2]

8. It is important that professionals provide an appropriate setting and support individualized to the family's needs to promote the assessment process. [D2]

HEALTH EVALUATIONS OF YOUNG CHILDREN WITH DOWN SYNDROME

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

General Approach to the Health Assessment

This section provides recommendations about general evaluations of health status for children with Down syndrome.

Early Intervention Policy ❖ An assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation. Whenever possible, the health assessment should be completed by the child's primary health-care provider.

Aspects of health evaluations reviewed

It would be an extremely large task to evaluate the efficacy of all possible methods for assessing health status in children with Down syndrome. Therefore, the scope of this section is limited to the following:

- The general health evaluation process for children with Down syndrome
- The general approach to assessing a few associated health conditions commonly seen in children with Down syndrome

Primary reasons for health evaluations of children with Down syndrome

There are three primary reasons for evaluating the health of children with Down syndrome:

- To provide a general assessment of the child's health status (as is recommended for all children with possible developmental delays or disorders)
- To identify health problems that occur more commonly in children with Down syndrome
- To determine the possible relevance of any identified problems to assessment and intervention

Medical conditions commonly seen in or associated with Down syndrome are listed in Table 15 (page 101).

Recommendations (General Approach to the Health Assessment)

General health surveillance

1. It is recommended that children with Down syndrome receive the same general routine preventive health care as typically developing children. In addition, it is recommended that physicians become familiar with and follow the general health-care guidelines published by medical specialty groups, such as:
   - The American Academy of Pediatrics, Committee on Genetics guidelines for providing medical care for children with Down syndrome (American Academy of Pediatrics 1994)
   - Health Care Guidelines for Individuals with Down Syndrome: 1999 Revision (published in *Down Syndrome Quarterly*) (Cohen 1999) [D2]

Early Intervention Policy ❖ Although assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation, medical tests (such as MRIs, metabolic tests, and genetic tests) are not reimbursable under the NYS Early Intervention Program. The service coordinator can and should assist the family in accessing these and other health-care services through their primary health-care providers. Supplemental physician evaluations may be accessed if appropriate and necessary to establish a child's eligibility for early intervention services, or to conduct an in-depth assessment of the child's physical development if there are specific concerns or problems in this developmental area.

2. It is recommended that physicians use Table 13 as a general guide for age-specific health examinations of young children with Down syndrome. [D2]

3. It is recommended that the primary care physician be responsible for the child's general health surveillance, and that the primary care physician consult with other health professionals as needed. (These might include, for example, a developmental/behavioral pediatrician, medical geneticist, cardiologist, endocrinologist, ophthalmologist, otolaryngologist, and audiologist.) [D2]

General health assessment considerations

4. It is important for the physician to be aware of the services the child is receiving. It is recommended that early intervention professionals and parents share the child's progress reports and communicate regularly with the child's physician about assessment results and the services the child is receiving. [D2]

5. When health-care providers and early intervention professionals are sharing information about a child, it is important that those sharing the information have the family's consent for release of information. [D2]

Early Intervention Policy ❖ The evaluator must submit a written summary and upon request, a full evaluation report, to the parent, Early Intervention Official, and with parental consent, the child's primary health-care provider. Health-care providers may also request a copy of the Individualized Family Service Plan from parents.

Table 13: Age-Specific Health Examination Recommendations for Young Children With Down Syndrome

Neonatal (Birth to 1 month)

- Confirm the diagnosis of Down syndrome; review the karyotype with the parents and provide them with a copy
- Review prenatal diagnosis and recurrence risk in subsequent pregnancies
- Discuss potential clinical manifestations, including:
  - Feeding problems (including gastroesophageal reflux)
  - Middle ear problems and hearing impairment
  - Hypotonia (decreased muscle tone)
  - Facial appearance
  - Vision problems

Table 13: Age-Specific Health Examination Recommendations for Young Children With Down Syndrome

- Heart defects (seen in about 50% of children with Down syndrome)
- Duodenal atresia
- Leukemia (less than 1% risk in children with Down syndrome; leukemoid reactions are more common)
- Congenital hypothyroidism (1% risk)
- Increased susceptibility to respiratory tract and sinus infections

▪ Perform focused medical evaluations to look for:
  - Vision problems (check for strabismus, cataracts, and nystagmus at birth or by 6 months)
  - Heart defects (echocardiogram recommended)
  - Duodenal atresia

▪ Discuss unproven therapies

Infancy (2 to 12 months)

▪ Review developmental milestones and elicit parent concerns regarding the child's development, and vision and hearing status

▪ Refer for comprehensive audiologic assessment by 6 months. Review the risk of otitis media with effusion and associated hearing loss (60-80% risk in children with Down syndrome)

▪ Check for strabismus, cataracts, and nystagmus by 6 months. Check vision at each visit. Refer the infant to an ophthalmologist by 6 months

▪ Perform thyroid screening tests at 6 and 12 months. Thyroid screen should include measurement of TSH as well as T_4

▪ Monitor the infant's growth and development (see growth and development information for age 1-3 years). Monitor head growth using NCHS charts for typically developing children

Early Childhood (1 to 3 years)

▪ Review developmental milestones and elicit parent concerns regarding the child's development, and vision and hearing status

▪ Have the child's hearing checked by an audiologist every six months until age 2, and then annually

▪ Have the child's vision checked annually by an ophthalmologist

(Continued from previous page)

Table 13: Age-Specific Health Examination Recommendations for Young Children With Down Syndrome

- Check dental status; have dental semiannual exam starting at age 2, or sooner if indicated
- Monitor growth and development
  - Down syndrome-specific growth charts can be used to assess length and weight relative to other children with Down syndrome (available at **www.growthcharts.com**)
  - National Center for Health Statistics (NCHS) growth charts for typically developing children can be used to assess weight to length ratio (available at **www.cdc.gov/nchs**)
  - Body mass index (BMI) can be used to measure weight for height beginning at approximately 2 years when an accurate stature can be obtained (available at **www.cdc.gov/nchs**)
- Perform thyroid screening tests annually. Screening should include measurement of TSH as well as T_4
- Screen for signs and symptoms of possible celiac disease by parent report (malabsorption, steatorrhea, failure to thrive)
- At 3 to 5 years, obtain radiographs for evidence of atlantoaxial instability or subluxation

Adapted from: American Academy of Pediatrics 1994
(Continued from previous page)

Assessment of Growth, Nutrition, and Metabolism

Issues relating to growth, nutrition, and metabolism are very important for all young children, but these areas take on particular importance for infants and young children with Down syndrome. This is, in part, because the growth patterns for almost all children with Down syndrome are quite different from typically developing children. In addition, children with Down syndrome are more likely to have feeding problems and other health conditions (such as cardiac problems) that will affect their nutrition and growth.

A standard method for assessing growth and nutritional status of all infants and young children is to compare their length (or height) and weight to standardized growth charts. Such standardized growth charts have been developed by analyzing data on large samples of children intended to be representative of the general population. Using these charts, a child's weight and height can be

compared with others of their same chronologic age. A child whose height is above the shortest 10 percent of the children in that age group is said to be at the 10th percentile for height, while a child whose height is greater than exactly half of the children of the same age would be at the 50th percentile. For the general population of children, there are separate growth charts for length (height), weight, weight to length ratio, and head circumference. The most commonly used growth charts for the general population is from the National Center for Health Statistics (NCHS, CDC, 2000).

It is well recognized that children with Down syndrome are generally shorter than children of the same chronologic age. This is often referred to as *growth delay*. For this reason researchers have developed separate Down syndrome-specific growth charts for length and weight, based on data from a general population of children with Down syndrome. While head circumference also is smaller among children with Down syndrome, there is no comparably detailed Down syndrome-specific growth chart for head circumference.

Another important area is determining nutritional requirements and assessing the diets of children with Down syndrome. This is of particular relevance for children with Down syndrome who have cardiac conditions or other health problems that may present special nutritional requirements. In addition, as children with Down syndrome grow older, they have a tendency to become overweight, so ongoing assessment of growth, nutrition, and metabolism is important.

Other issues of concern relate to the role of thyroid and growth hormone in the growth of children with Down syndrome. A small percentage of children with Down syndrome will have hypothyroidism: approximately one percent have congenital hypothyroidism (have the condition at birth), and approximately 15 percent develop the condition when they are older. If untreated, hypothyroidism will affect growth and development, and contribute to other health problems. The use of growth hormone therapy to stimulate the growth of children with Down syndrome is a controversial topic.

Basis for the growth, metabolism, and nutrition recommendations

A systematic review of the extensive scientific literature on growth, nutrition, and metabolism for young children was not done. The literature review focused on assessment of growth, and thyroid and growth hormone specific to growth, nutrition, and metabolism for young children with Down syndrome. Some of the consensus recommendations are based on information from review articles or other publications that do not meet the criteria for evidence for this guideline.

Recommendations (Assessment of Growth, Nutrition, and Metabolism)

Assessment of growth

1. In assessing the growth of a child with Down syndrome, it is recommended that the child's length and weight be monitored and assessed using Down syndrome-specific growth charts. However, it is important to recognize that the Down syndrome-specific charts reflect a tendency for children with Down syndrome to be overweight by the age of 36 months, and therefore it is recommended that weight for length be assessed using growth charts for typically developing children.

   [C] (Castells 1996)

2. It is important to include a nutrition and diet assessment when considering the possible cause(s) of altered growth, either underweight or overweight, in young children with Down syndrome. [D2]

Early Intervention Policy ❖ Nutrition services are included as an early intervention service. A nutrition assessment can be included as part of the multidisciplinary evaluation as a supplemental evaluation or when identified as an area of need, and can be provided as a supplemental evaluation at any time when included in the Individualized Family Service Plan (IFSP).

Assessing nutritional status and needs

3. In assessing the nutritional needs of a child with Down syndrome (caloric need for growth/prevention of obesity), it is important to recognize that most children with Down syndrome need fewer calories than a typically developing child of the same age and height. [D2]

4. In assessing caloric needs, intake, and growth of a child with Down syndrome, the nutrition assessment needs to take into account that children with congenital heart disease or breathing difficulties frequently have increased energy requirements and may have poor growth. [D2]

Assessing feeding relationships and behaviors

5. It is important to consider the feeding relationship between the parent/caregiver and the child when assessing a child's feeding/intake and nutrition status. While the relationship may affect intake and nutrition, poor growth and poor feeding may likewise affect the relationship. [D2]

6. It is important to include an assessment of behavioral feeding difficulties when evaluating a child's feeding and dietary intake. [D2]

Thyroid assessment

7. Thyroid disease is more common in children with Down syndrome, and symptoms of thyroid disease often mimic symptoms generally associated with Down syndrome. Therefore, it is recommended that thyroid function (T_4 and TSH) be tested as part of newborn metabolic screening at the age of 6 months and yearly thereafter.

   [C] (Cutler 1986, Sharav 1991)

Oral-Motor and Feeding Assessment

Infants and young children with Down syndrome often have a variety of oral sensorimotor problems and feeding issues. Some of these problems may relate to physical factors seen in children with Down syndrome, such as hypotonia (low muscle tone). In addition, some children with Down syndrome may have other health problems that interfere with feeding.

Assessment of oral sensorimotor and feeding problems in infants and young children is often done by a multispecialty team of health-care specialists that may include any of the following: a pediatrician, a speech-language pathologist, a registered dietitian, an occupational therapist, a psychologist, an otolaryngologist, and a gastroenterologist.

Basis for oral-motor and feeding recommendations

The methods used for identifying and assessing oral-motor and feeding problems in children with Down syndrome are similar to the methods for other children. Therefore, while there is an extensive literature on assessment of oral-motor and feeding problems in young children, it was beyond the scope of this guideline to review critically all of this literature. The recommendations in this section are considered consensus recommendations, aided by the panel's professional experience and cumulative knowledge of the literature.

Recommendations (Oral-Motor and Feeding Assessment)

Components of an oral-motor and feeding assessment

1. It is recommended that an oral-motor and feeding assessment include:
   - Physical examination and thorough medical and feeding history

- Observation of interaction patterns between child and primary feeders, including observation of trial feeding
- Body posture and positioning effects
- Oral-motor examination, including:
  - Presence/absence of oral reflexes
  - Structure and praxis of lips, tongue, palate
  - Oral sensation
  - Laryngeal function (voice production)
  - Control of oral secretions
  - Respiratory control
  - Swallowing function (including effect on nutrition intake and need for measures to prevent aspiration)
  - Oral postural control
- Parents knowledge about the progression of introducing solid foods to the child's diet
- Indications for specialized studies (such as videofluoroscopy) [D2]

Early Intervention Policy ❖ An oral-motor and feeding assessment can be included as part of the multidisciplinary evaluation or as a supplemental evaluation when included in the Individualized Family Service Plan (IFSP).

Conducting the assessment

2. It is important to consider developmental rather than chronologic age when evaluating feeding skills. [D2]

3. It is recommended that the professionals involved in the assessment of children with oral-motor and feeding concerns have knowledge of normal oral-motor and feeding development as well as experience and expertise in assessing young children with such problems. [D2]

4. It is useful to have a team of pediatric professionals involved in ongoing assessment of children for whom there are concerns about oral-motor function or feeding. Team members might include:
   - Speech-language pathologist
   - Occupational therapist

- Registered dietician
- Primary health-care provider
- Developmental pediatrician
- Psychologist
- Gastroenterologist
- Otolaryngologist [D2]

Ongoing monitoring when feeding

5. It is important to monitor health and behavioral indicators for signs of child stress during oral feeding times. For example:
   - Coughing, gagging, or gurgly voice quality
   - Extended meal times (more than 30 minutes)
   - Breathing difficulties (increased effort or increased rate, blue lips)
   - Food refusal at feeding times (e.g., turning head away, pushing food away)
   - Fatigue (falling asleep)
   - Fussing/crying
   - Reflux/vomiting [D2]
6. It is recommended that for feeding problems, both the needs of the infant and the mother be assessed and appropriate guidance given:
   - It is important to consider the child's functional and behavioral capabilities that contribute to successful breast or bottle feeding
   - Referral to a lactation specialist or other qualified professional (e.g., nurse, pediatrician) may be beneficial in assisting the mother to address breast-feeding concerns [D2]

Assessment tests

7. Commercially available clinical assessment tests may sometimes be useful aids in assessing oral-motor and feeding problems in some infants and young children. Examples of such tests are:
   - The Neonatal Oral-Motor Feeding Scale
   - The Pre-Speech Assessment Scale
   - Schedule for Oral-Motor Assessment (SOMA) [D2]

Assessment of Hearing and Vision Status

Vision and hearing problems are seen more commonly in young children with Down syndrome than among the general population of young children (Pueschel 1990). Children with Down syndrome have an increased prevalence of strabismus, cataracts, and several other types of eye problems. Although some of these conditions can be discovered on physical examination, such as cataracts (an opacity of the lens in the eye) or strabismus (a muscle imbalance of the eye muscle in which the eyes do not track together), it may be difficult for general pediatricians to recognize some of the eye conditions often associated with Down syndrome.

Assessing vision in very young children can be difficult. A visual evoked potential examination is a test that measures electrical activity in the visual cortex of the brain after the child receives a visual stimulus. As a child grows older, standard vision tests often require the child to provide verbal responses to visual stimuli.

It is also well known that hearing problems are much more common among children with Down syndrome than in the general population. One reason for this is that otitis media with effusion (OME) is very common in children with Down syndrome. OME is characterized by the presence of fluid in the middle ear, which often results in some degree of mild to moderate temporary conductive hearing loss. Often, it initially occurs after an ear infection (acute otitis media). In young children with Down syndrome, the OME may persist long after the acute infection has resolved. Also, the incidence of sensorineural hearing loss (inner ear) is also somewhat higher among children with Down syndrome than in the general population.

Basis for vision and hearing recommendations

Recommendations on assessment of vision and hearing problems are consensus recommendations of the panel. A comprehensive evaluation of the scientific literature related to the assessment of vision and hearing was beyond the scope of this guideline. Although a systematic literature search was not done on these topics, information from review articles and other publications was used.

Recommendations (Assessment of Hearing and Vision Status)

Monitoring for otitis media

1. Because of the increased risk for otitis media with effusion (OME) and the potential for related hearing loss, it is important that young children with

Down syndrome be assessed for possible middle ear infection (otitis media) whenever fever or other signs or symptoms of upper respiratory infection are present. [D2]

Early Intervention Policy ❖ Health-care services that are routinely needed by all children are not reimbursable under the Early Intervention Program (EIP) as early intervention services. Medical surveillance of otitis media should be provided as a part of primary health care by the child's primary health-care provider.

2. It is recommended that in infants and very young children, neither otoscopy or tympanometry be used in isolation to diagnose middle ear effusion because they are sometimes not reliable. [D2]

3. If a child's general pediatrician is not able to visualize the eardrum, it is recommended that the child be referred to a specialist, preferably a pediatric otolaryngologist (ear, nose, and throat/ENT specialist physician). It may be difficult to visualize the drum in children with Down syndrome because they tend to have narrow external canals that may be prone to blockage from excess cerumen (ear wax), auditory canal stenosis, or viscous mucus. [D2]

4. For children with middle ear problems, it is recommended that frequent monitoring of hearing be done by an audiologist, and that the child be seen by a nose and throat (ENT/otolaryngologist) physician, preferably a pediatric otologist, on a regular basis. [D2]

Assessment of hearing

5. Even if there is no concern about hearing loss, it is recommended that all children with Down syndrome have ongoing monitoring and periodic audiologic testing of their hearing. [D2]

6. It is recommended that all children with Down syndrome who are having middle ear problems have a comprehensive hearing assessment by an audiologist (one that includes ABR). For children with recurrent otitis media, it is recommended that audiologic testing be considered as often as every six months during the first two years and then annually. This is important for young children with Down syndrome because:
   - Hearing is a key component of oral language development

- There is a high incidence of conductive hearing loss that may result from the increased incidence of otitis media with effusion (OME)
- Screening will not always detect a mild hearing loss
- There may be progressive sensorineural hearing loss
- It is difficult to detect a mild hearing loss by observation [D2]

Components of a comprehensive hearing assessment

7. It is recommended that a comprehensive assessment of hearing for infants and young children (from birth to 3 years old) include the following as components of an audiometric test battery (see Table 14, page 98):
   - Hearing history
   - Behavioral audiometry testing (using developmentally appropriate procedure)
   - Electrophysiologic procedures, as needed [D2]
8. Physiologic tests that may require sedation, such as the auditory brainstem response (ABR), are recommended for children whose hearing assessment results are unreliable or inconsistent, and their auditory status remains unknown. ABR is an appropriate test for children suspected of hearing loss who are too young (<6 months) or who are not able to participate reliably for behavioral test procedures. [D2]

Assessment of vision

9. It is recommended that a routine vision evaluation be conducted soon after Down syndrome is diagnosed. [D2]
10. Because congenital cataracts occur more frequently in infants with Down syndrome than in other children, it is recommended that children with Down syndrome be examined for congenital cataracts at birth or as soon as the diagnosis is made. [D2]
11. It is recommended that all children with Down syndrome be seen by a pediatric ophthalmologist or pediatric optometrist within the first 6 months of life and annually thereafter. [D2]
12. It is recommended that general vision checks be done as part of the child's routine health-care visits. It is important to check for strabismus and nystagmus as part of each general vision check. [D2]

Table 14: Components of a Comprehensive Hearing Assessment

Hearing History

- History of otitis media (ear infections and fluid in the middle ear)
- Auditory behaviors (reacting to and recognizing sounds)
- Parents' general concern about hearing and communication

Behavioral Audiometry Testing

- *Behavioral Observation Audiometry*. Observation of changes in behavior in response to speech and to sounds of known intensity and frequency (for example, speech, music, narrow bands of noise). This is an unconditioned behavioral response procedure.
- *Visual Reinforcement Audiometry (VRA)* and *Conditioned Orienting Response Audiometry (COR)*. Used to determine threshold sensitivity in infants beginning at approximately 6 months of age (developmental age). A head turn response upon presentation of an audiometric test stimulus is rewarded by the illumination and activation of an attractive animated toy.
- *Conditioned Play Audiometry (CPA)*. Used to determine threshold sensitivity in young children beginning at approximately 2 years of age (developmental age). A play response (block drop, ring stack) in response to an audiometric test stimulus is rewarded by social praise.

Electrophysiologic Procedures

- *Tympanometry*--assesses the mobility of the eardrum (it is not a direct test of hearing). A probe attached to a soft, plastic ear tip is placed at the ear canal opening and air pressure is varied in the ear canal.
- *Acoustic Reflexes*--an involuntary middle ear muscle reflex to sounds is recorded, usually elicited by moderately loud tones or noises.
- *Evoked Otoacoustic Emissions (EOAE)*--assesses the function of the outer hair cells of the cochlea by recording a cochlear echo. A probe attached to a soft ear tip is placed at the ear canal opening. A microphone delivers clicks or tones. Another sensitive microphone within the ear tip records the cochlear echo.
- *Auditory Brainstem Response (ABR)* or *Brainstem Auditory Evoked Response (BAER)*--used to estimate hearing threshold sensitivity using clicks or tones and to determine the integrity of the auditory pathway from the cochlea to the level of the brainstem.

Adapted from: New York State Department of Health, Clinical Practice Guidelines, Communication Disorders 1999

Assessment of Other Associated Health Conditions

A variety of health conditions are seen more commonly in children with Down syndrome compared with the general population. Identification of many of these conditions often occurs through obtaining a physical examination, a health history, or specific diagnostic tests.

Most of the methods for identifying and assessing these problems are the same whether or not children have Down syndrome, and therefore specific information about the assessment of these conditions is considered beyond the primary scope of this guideline.

Basis for the recommendations

Although the literature for this topic is extensive, a comprehensive literature review was not done. The recommendations are based on panel opinion making use of information found in review articles and the panel's general knowledge of the literature and professional experience in these areas.

Recommendations (Assessment of Other Associated Health Conditions)

1. Because there are a variety of health conditions commonly seen in children with Down syndrome, routine medical evaluations are very important. It is recommended that children with Down syndrome be routinely screened for these conditions. General recommendations for health examinations are presented in Table 13 (page 87). Some of the medical conditions commonly associated with Down syndrome are listed in Table 15 (page 101). [D2]

Early Intervention Policy ❖ Although assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation, medical tests (such as MRIs, metabolic tests, and genetic tests) are not reimbursable under the NYS Early Intervention Program (EIP). The service coordinator can and should assist the family in accessing these services through their primary health-care providers. Supplemental physician evaluations may be accessed if appropriate and necessary to establish a child's eligibility for early intervention services, or to conduct an in-depth assessment of the child's physical development if there are specific concerns or problems in this developmental area.

2. Because heart defects are so common in children with Down syndrome, it is recommended that within the first month after birth, children receive a cardiac evaluation, including an echocardiogram. [D2]

3. During the first week of life, it is important to be on the lookout for any congenital anomalies involving the gastrointestinal tract, for example:
   - Persistent vomiting
   - Abdominal distention
   - Limited or no passage of stool
   - Failure to thrive [D2]
4. During early childhood, it is important to screen for signs of digestive disorders such as celiac and Hirschsprung disease. [D2]
5. At age 3 to 5 years, it is recommended that radiographs be obtained to screen for evidence of atlantoaxial instability or subluxation. [D2]
6. It is important to check the child's dental status with semiannual exams beginning at age 2, or sooner if indicated. [D2]

Early Intervention Policy ❖ Dental care is not an early intervention service.

Table 15: Common Associated Conditions in Children With Down Syndrome *(repeated from Table 1, page 20)*

	Percent of children affected
Congenital heart disease	40
Hypothyroidism	10–20
Joint laxity	15
Psychiatric disorders in adolescence	13
Gastrointestinal tract defect	12
Alopecia (hair loss)	10
Seizures	6
Leukemia	1
Obesity	50
Dental problems (hypodontia, malocclusion)	60–100
Hearing loss	60–80
Vision problems:	
• cataracts	3
• refractive errors	70
• strabismus	50
• nystagmus	35

Adapted from: Pueschel 1990

CHAPTER IV: INTERVENTION

Topics included in this chapter

- General Approach to Interventions for Young Children With Down Syndrome
- Interventions Specific to the Developmental Characteristics of Young Children With Down Syndrome
- Specific Intervention Approaches
- Health-Related Interventions

Evaluating Intervention Issues

This chapter provides recommendations about appropriate interventions for young children with Down syndrome. When available, scientific evidence about the efficacy of specific intervention methods was used as the basis for developing these guideline recommendations. When such evidence was not available, guideline recommendations were made based on consensus opinion of the guideline panel.

Over the past decade, there has been an increasing emphasis on outcomes research in the fields of health care, social services, and education. A primary focus of outcomes research is to evaluate how specific interventions affect functional outcomes for individuals and families. This is sometimes also known as treatment efficacy research. (Efficacy refers to the degree to which an intervention leads to a beneficial result when tested in a controlled environment.)

In evaluating interventions for children with developmental problems, the goal of outcomes research is to answer the following important questions:

- Is the intervention efficacious in improving important functional outcomes?
- Does one type of intervention work better than another?
- What specific target behaviors, skills, or health factors associated with this condition/ problem are altered by the intervention?

When evaluating interventions for children with Down syndrome, it is important that appropriate research designs be used to determine if the outcomes observed are clearly due to the intervention evaluated. Most young children, even those with Down syndrome, progress developmentally with time alone (this is often referred to as a *maturation effect*). Therefore, in evaluating the efficacy of interventions for young children, it is important to determine if the intervention

brings about improvement in a child's development over and above what would be expected to occur by maturation alone.

GENERAL APPROACH TO INTERVENTIONS FOR YOUNG CHILDREN WITH DOWN SYNDROME

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

GENERAL CONSIDERATIONS FOR PLANNING AND IMPLEMENTING INTERVENTIONS

The general considerations for planning and implementing interventions for children with Down syndrome are, for the most part, similar to the considerations involved in intervention planning for children with any condition. Decisions regarding intervention for a particular child are linked closely with that child's assessment results, so the intervention can be individualized to the child's strengths and needs as well as the family's strengths, needs, and goals.

Children with Down syndrome are usually identified at birth or soon thereafter, and, therefore they tend to enter into intervention at an earlier age than do children with other conditions. As the child matures over time, the types of intervention and the frequency of intervention most appropriate for a particular child with Down syndrome and his or her family will probably change. It is important that decisions about changes in a child's intervention are based on ongoing monitoring of the child's progress and the family's needs. There is no single intervention approach or strategy that will be appropriate for all children with Down syndrome.

Children with Down syndrome tend to have problems in all developmental domains and are at risk for many medical problems. Because there are a variety of professionals that may be involved with the child and the family of a child with Down syndrome, teamwork and collaboration between the professionals is especially important.

Recommendations (General Considerations for Planning and Implementing Interventions)

Importance of early identification and intervention

1. It is important to identify children with Down syndrome and begin appropriate interventions as soon as possible since such early intervention may help speed the child's overall development and lead to better long-term functional outcomes. It is recommended that appropriate assessment and intervention be provided as soon as possible after a diagnosis of Down syndrome has been made.

   [C] (Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Sanz 1996)

Early Intervention Policy ❖ Early intervention services should begin as soon as possible to mitigate developmental delays associated with Down syndrome. A child with Down syndrome does not need to be experiencing a developmental delay in a specific area to begin services. The IFSP should include services needed to address agreed-upon goals and measurable outcomes for the child and family.

Initiating intervention

2. When Down syndrome is diagnosed, it is important to initiate assessments to determine appropriate interventions to address all developmental domains. It is appropriate to begin this process at the time of diagnosis. It is not necessary to wait for a developmental delay to initiate an ongoing assessment and intervention process. [D1]

Early Intervention Policy ❖ All children in the Early Intervention Program must receive a multidisciplinary evaluation—even children with a diagnosed condition that makes them eligible for the program. The multidisciplinary evaluation is important to understanding the child's developmental status and priorities, resources, and concerns of the family.

3. Although it is recommended that the assessment and intervention process begin at the time of diagnosis, it is important for parents to understand that children who receive intervention at a later age may still benefit from the intervention. [D2]

4. It is important to recognize that assessing the need for and initiating appropriate family support is an important component of providing early intervention services for the child and family. [D2]

Early Intervention Policy ❖ In New York State, an Individualized Family Service Plan (IFSP) must be in place for children within 45 days of referral to the Early Intervention Official. The IFSP must include a statement of the major outcomes expected for the child and family and the services needed by the child and family. The IFSP must be reviewed every six months and evaluated annually. Information from ongoing assessments should be used in IFSP reviews and annual evaluations.

Individualizing interventions based on information from the assessment

5. It is important to recognize that while young children with Down syndrome may share many common characteristics, they differ in terms of their individual strengths and needs, as well as their responses to specific intervention methods or techniques. There is no one specific intervention approach or plan that is effective for all children with Down syndrome. Furthermore, children have different family situations, and some families will need more support than others. It is recommended that the use of any intervention for a child with Down syndrome be based upon an assessment of the specific strengths and needs of the child and family. [D2]

Early Intervention Policy ❖ Early Intervention services must be included in an Individualized Family Service Plan (IFSP). The IFSP is provided at no cost to parents, under the public supervision of Early Intervention Officials and State Department of Health, and by qualified personnel as defined in State regulation (see Appendix D).

Early Intervention Policy ❖ The type, intensity, frequency, and duration of early intervention services are determined through the Individualized Family Service Plan (IFSP) process. All services in the IFSP must be agreed to by the parent and the Early Intervention Official. When disagreements about what should be included in the IFSP occur, parents can seek due process through mediation and/or an impartial hearing.

An IFSP may be amended any time the parent(s) and the Early Intervention Official agree that a change is needed to better meet the needs of the child and family.

Selecting intervention strategies and targets

6. In making a decision either to start or change a specific intervention for a child with Down syndrome, it is important that parents and professionals consider:
   - The best available scientific evidence about the effectiveness of the intervention and alternatives
   - Developmental needs and skills of the child
   - Potential risks or harms associated with the intervention [D2]
7. When selecting intervention strategies, goals, and objectives, it is important that they:
   - Be developed in conjunction with the participation of the parents
   - Be appropriate to the particular culture of the family
   - Take into consideration the motivation of the child [D2]
8. It is important to work with the parents to determine appropriate and acceptable ways to include the parents/family and other caregivers in facilitating progress towards the intervention goals. [D2]
9. It is recommended that target behaviors for each individual child be clearly identified and defined with developmentally appropriate measurable criteria for mastery. [D2]
10. A comprehensive model of intervention strategies is recommended for most young children with Down syndrome. A comprehensive model includes the opportunity for both home and/or community/center-based services, as well as family support services. It is important to develop strategies specific to the needs of the child and family. [D2]

11. When making decisions about interventions for a child with Down syndrome, it is recommended that parents seek guidance from qualified professionals with experience in working with young children with Down syndrome. [D2]

Determining the intervention setting

Early Intervention Policy ❖ Early Intervention services can be delivered in a wide variety of home- and community-based settings. Services can be provided to an individual child, to a child and parent or other family member or caregiver, to parents and children in groups, and to groups of eligible children. (These groups can also include typically developing peers.) Family support groups are also available.

12. In determining the most appropriate settings for interventions, it is important to consider the following factors:
    - The child's home environment
    - The family's readiness
    - The cognitive, social, communication, and motor development of the child (ability to follow directions, sit still, interact with peers, etc.)
    - The child's response to current intervention
    - Health status and associated health conditions [D2]
13. It is important to consider the family's readiness to accept changes in the intervention settings (such as from the home to more community-based or group settings). [D2]

Ongoing monitoring and appropriate modification of the intervention

Early Intervention Policy ❖ The Individualized Family Service Plan (IFSP) must be reviewed every six months and evaluated on an annual basis. This may include an evaluation of the child's developmental status, if needed. After the child's initial multidisciplinary evaluation, supplemental evaluations may also be conducted when recommended by the IFSP team, agreed upon by the parent and Early Intervention Official (EIO), and included in the IFSP.

The IFSP may be amended any time the parent(s) and the EIO agree that a change is needed to better meet the needs of the child and family.

Providers of early intervention services are responsible for consulting with parents and other service providers to ensure the effective provision of services and to provide support, education, and guidance to parents and other caregivers regarding the provision of early intervention services.

14. It is recommended that ongoing assessment be linked to all interventions to determine if therapy goals are being met or if changes in the type or amount of intervention are needed. [D2]

15. It is recommended that parents and professionals consider the need to modify or discontinue a specific intervention when:
    - The child has progressed and target objectives have been achieved
    - Progress is not observed after an appropriate trial period
    - The child has shown some progress, but target objectives have not been achieved after an appropriate trial period
    - There is an unexpected change in a child's behavior or health status
    - There is a change in the intervention setting (such as moving from the home to a center-based setting)
    - There is a change in family priorities [D2]

16. It is recommended that parents be provided with the knowledge that the types of intervention and frequency of intervention may change over time. It is important for parents to understand that interventions may need to be adjusted based on ongoing reassessment of the child's progress and needs. While adjusting the intervention often means increasing or decreasing the frequency or intensity, it is also important to consider the need to change some aspect of the approach or the setting. [D2]

17. Elements of single-subject study design methodology (Table 16), adapted to the clinical setting, may be useful for monitoring the child's progress and the effectiveness of specific intervention techniques. [D2]

Periodic in-depth reassessment and evaluation

18. In addition to ongoing monitoring, it is recommended that periodic in-depth reassessment of the child's progress and developmental status be done at least once every 6 to 12 months. As part of the periodic in-depth reassessment of the child, it is important to:
    - Include appropriate standardized testing to assess the child's progress
    - Include appropriate qualitative information about the child's development and progress
    - Assess the child's progress and functional level and compare these to the child's age-expected levels of development and functioning [D2]
19. In addition to ongoing monitoring and reassessment, it is important to perform periodic comprehensive evaluations to assess the child's individual progress. It is recommended that a child's progress be considered with respect to age-expected development for both children with Down syndrome and typically developing children. [D2]
20. It is recommended that a comprehensive evaluation include both qualitative information and appropriate standardized testing of the child's progress. [D2]

Table 16: Single-Subject Study Design Methodology

Single-subject methodology is an approach to determine the effect of an intervention on an individual:

- Acceptable single-subject study designs are based on repeated controlled application of the intervention to demonstrate its effectiveness and use appropriate control conditions to evaluate the degree of change as compared with preintervention behavior.
- Single-subject design studies involve systematically observing and recording repeated measurements of an individual's specific behaviors (the frequency of the behavior within a discrete time period) on a graph. Patterns are visually analyzed to determine if the changes in behavior are due to the intervention.

Commonly Used Single-Subject Designs

Within Series: Sequential implementation

- A-B-A
- A-B-A-B
- Other A-B permutations

Between Series: Concurrent implementation

- Alternating treatments
- Simultaneous treatments

Combined Series: Multiple baseline

- Multiple baseline across behaviors
- Multiple baseline across settings
- Multiple baseline across individuals
- Multiple baseline – permutations of the above

The purpose of these study designs is to differentiate between normally occurring variation in the person's behavior and the effects of the intervention. The term "A" is used to identify a period when no treatment is given, and the term "B" refers to the intervention phase, in which the treatment procedure is introduced in a controlled fashion. Multiple baseline designs refer to conducting measurement of several dependent variables, subjects, or settings simultaneously to examining sources of possible extraneous factors that may be influencing behavior change.

Collaboration, coordination, and integration

21. It is important that techniques and approaches are coordinated, integrated, and collaborative across all individuals working with the child and family,

and that those individuals working with the child communicate with each other about the child's progress. [D2]

22. It is important that there be appropriate supervision of paraprofessional staff. [D2]

Early Intervention Policy ❖ Early Intervention services must be provided by qualified personnel. "Paraprofessionals"—individuals who do not have a professional license or certification—can only assist in the provision of group developmental intervention services under the supervision of a qualified professional. For a list of qualified personnel, see Appendix D.

23. When planning a comprehensive intervention program for a child with Down syndrome, it is recommended that if multiple intervention components are used, then careful consideration be given to integrating the intervention approaches and/or components to make sure they are compatible and complementary. [D2]

Addressing coexisting developmental and health problems

24. It is essential that all providers who work with young children with Down syndrome:
    - Understand the developmental and medical problems commonly associated with Down syndrome and the implications for the specific intervention provided
    - Receive relevant information about the child's health status and associated health conditions, such as cardiac or respiratory problems, hearing loss and need for alternative communication strategies, or other considerations that may affect the way that the intervention is implemented
    - Understand the importance of monitoring the child's health status and tolerance for motor activities during the intervention [D2]

25. Because young children with Down syndrome tend to be susceptible to colds, otitis media, and other infections, it is important that any center-based program serving children with Down syndrome ensure the consistent practice of good infection control policies and procedures. [D2]

Need for scientific validation of efficacy and safety of interventions

26. It is recommended that in selecting interventions for young children with Down syndrome, scientific evidence for efficacy be an important consideration. [D2]

27. It is recommended that scientifically valid research continue to be done on the effectiveness of interventions for young children with Down syndrome, especially for "alternative" interventions that make claims with no scientific evidence to document efficacy. [D2]

Including the Parents and Family in Planning and Implementing Interventions

For all children, including children with Down syndrome, the family plays an extremely vital role. The child's needs can be understood only within the context of the family and the family's culture. Intervention services are the most effective if they are matched to the strengths and needs of the family as well as the strengths and needs of the child. Further information about the family assessment is presented in Chapter III (page 80).

Inclusion of the parents and family in decisions about interventions is a necessity. Because Down syndrome is identified at birth, infants with Down syndrome tend to begin the assessment and intervention process at a very early age. Many of the early interventions may focus on the parents rather than the infant. For example, interventions may focus on the parents' need for information or their need for social support. Even for interventions that involve a professional working directly with the child, informal or formal parent training may be an important component of the intervention. Social support and formal parent training interventions are discussed in greater detail later in this chapter.

Recommendations (Including the Parents and Family in Planning and Implementing Interventions)

Importance of parent involvement

1. It is recommended that, to the extent they are able, parents be involved in the assessment and intervention for their child in order to understand:
    - What to expect regarding their child's development
    - Intervention options
    - Intervention goals, objectives, and methods

- How to generalize and reinforce intervention approaches in the child's daily routines
- How to evaluate progress and provide feedback to professionals [D2]

Level of parental involvement

2. Because parental involvement is so important, it is recommended that parents be involved in deciding how they are best able to participate in supporting and facilitating intervention strategies and approaches for their child. [D2]

3. It is important to help parents understand that everyday interactions and play activities are opportunities for their child to learn and for reinforcing the learning that occurs in more formal intervention programs. It is important for parents to recognize that "interventions" can occur naturally in the parent-child relationship and that "interventions" do not occur only in the context of formal intervention programs. [D2]

Early Intervention Policy ❖ Providers of early intervention services are responsible for consulting with parents to ensure the effective provision of services and to provide support, education, and guidance to parents and other caregivers regarding the provision of early intervention services.

Providers and Early Intervention Officials must make reasonable efforts to ensure that an individualized approach is used in delivering services to children and their families, including consideration and respect for culture, lifestyle, ethnicity, and other family characteristics.

Role of the professionals working with the parents

4. It is important for professionals to support, encourage, and facilitate parent participation in the child's interventions.

   [B] (Bidder 1975, Bruder 1987, Girolametto 1988, Jago 1984, Kysela 1981, Poulson 1988, Purdy 1987, Sanz 1996, Sloper 1986)

5. It is recommended that professionals:
   - Work collaboratively with the parents to develop the intervention program
   - Elicit observations from the parents regarding the child's functioning
   - Share regular progress reports with the parents

- Give parents regular feedback based on direct observation of the child
- Consider the cultural perception of the role of the family in intervention [D2]

6. It is important for professionals to work with parents to identify strategies for parents to participate in the child's intervention, including approaches that will help parents to:
   - Enhance cognitive skills in everyday activities
   - Promote opportunities for generalization of developmental skills

   [B] (Bidder 1975, Bruder 1987, Girolametto 1988, Jago 1984, Kysela 1981, Poulson 1988, Purdy 1987, Sanz 1996, Sloper 1986)

7. It is recommended that professionals provide instruction/teaching to parents that is geared to the needs of the child and family, and will allow the parents to foster their child's development in all domains. Teaching can occur informally as needs/opportunities arise or in planned sessions, and methods could include verbal discussion and instruction, written material, supervision, videotapes, hands-on training, and participation in the child's therapy sessions.

   [B] (Bruder 1987, Girolametto 1988, Sanz 1996)

8. It is important that professionals are available to respond to parents' questions and needs. It is important that this be ongoing, as the questions and needs will change as the child develops. [D2]

Informing parents about interventions

9. It is important to inform and provide parents with information about:
   - What is known about the types and effectiveness of the various interventions that may be available
   - The intervention options that are appropriate and available for their child
   - The types of professionals who may be providing interventions and what they will be doing [D2]

Considering the cultural context of the child and family

10. A child's life is always embedded in a cultural context. It is always essential to consider and respect the family's culture and primary language when providing interventions for young children with developmental disabilities. [D2]

11. If the professional providing the intervention is not familiar with the culture of the family, it is recommended that a person familiar with the culture and language of the family review intervention techniques and materials to determine if they are culturally appropriate. [D2]
12. If an interpreter assists in the intervention process, it is important that the interpreter be trained to provide culturally and linguistically accurate interpretations of the child's behaviors. [D2]

Parent education and training

13. It is recommended that any intervention program provide opportunities for individual/family and/or group education and training. It is important to include specific teaching objectives in all structured parent training programs.

    [B] (Bruder 1987, Girolametto 1988)

Parent Training and Family Support

Social support is a broad concept that includes both informal and formal support, as well as both planned and naturally occurring interactions. Social support processes are complex and may affect behavioral outcomes of the parents, the child, and the family directly or indirectly.

Social support has the following five components:

- Relational – the existence and quantity of social relationships
- Structural – quantitative aspects of personal social networks
- Functional – the type, quantity, and quality of help provided
- Constitutional – the extent to which the support offered matches the indicated need for help
- Support satisfaction – the extent to which support is perceived as helpful

Intervention services, including social support services, are most effective if they are matched to the needs of the individual family. In a study by Affleck (1989), 94 mothers were assigned at random to either a group provided with professional support or a control group. For mothers with a high need for support, the effect of receiving the support was positive for outcome measures of the mothers' sense of competence, perceived control, and responsiveness. However, in mothers with a low need for support, receiving support had a negative effect on those outcome measures.

Experimental studies of social support interventions have found that the informal support approach may be more effective than formal support services are in producing positive outcomes of enhancing competencies and satisfaction in parents. Informal support is often characterized by psychological closeness and mutual caring that enhances competence and feelings of well-being. Informal social support is usually intended to support the parent/caregiver, but it may also have indirect influences on child outcomes, perhaps mediated through the parent/caregiver sense of well-being and interaction styles with the child.

Recommendations (Parent Training and Family Support)

Parent training

1. It is recommended that parent training programs be included as a component of the intervention plan for young children with Down syndrome. Training parents how to implement intervention strategies and approaches at home can promote consistency and reinforce the intervention, and may result in improved outcomes for the child. Common elements of effective parent training programs include:
   - Verbal instruction
   - Supervised practice
   - Feedback
   - Teaching the methods to other parents

     [C] (Bidder 1975, Bruder 1987, Kysela 1981, Piper 1980, Sanz 1996, Sloper 1986)

Family support

2. It is important to recognize that social support includes:
   - Both informal and formal support
   - Planned and naturally occurring interactions that may be related directly and/or indirectly to child, parent, and family functioning [D2]
3. When providing support to families, it may be useful to consider ways of helping the family to mobilize informal support networks rather than relying solely on a formal approach to support. [D2]

Early Intervention Policy ❖ Individual family counseling is an early intervention service. Family support groups are also a reimbursable early intervention service.

4. It is recommended that formal social support plans be developed in conjunction with the family to ensure that they match the needs of families. Not all families need the same level of support. [D2]
5. If professional support is given, it is recommended that this support be provided in response to an indicated need for particular kinds of information or resources and in a way that mirrors features found in informal support networks. [D2]
6. It is important to establish a collaborative parent-professional relationship in which the professionals are able to listen effectively and nonjudgmentally to family-identified needs. [D2]
7. It is important to recognize that social support is not a panacea but is merely one of many intrapersonal, interpersonal, and environmental factors affecting the functioning of children and their families. [D2]
8. In evaluating the effects of an intervention program, it is important to include family-related measures as well as child-oriented outcomes. [D2]

INTERVENTIONS SPECIFIC TO THE DEVELOPMENTAL CHARACTERISTICS OF YOUNG CHILDREN WITH DOWN SYNDROME

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

INTERVENTIONS FOCUSED ON COGNITIVE DEVELOPMENT

Cognition includes the processes of the brain that allow us to remember, think, act, feel emotions, and experience the environment. Cognitive processes are complex, diverse, and highly interrelated (Table 5, page 48). Interventions targeting cognitive development focus on both global and specific cognitive skills, such as attention to the environment, information processing, and memory.

Recommendations (Interventions Focused on Cognitive Development)

General approach

1. It is important to remember that there is not one specific cognitive intervention technique or theoretical model that is effective with all children. As with all interventions, it is recommended that the type, frequency/intensity, and setting of the intervention be based on an assessment of the child's overall developmental level (all domains) and the specific strengths and needs of the child and family. [D2]

2. It is recommended that development of cognitive skills be an ongoing process that is incorporated into all activities by professionals and by the family during the course of intervention and during all activities of daily life. [D2]

3. It is important to recognize that cognitive development may be enhanced when:
   - Intervention is provided at an early age
   - Participation in early intervention programs is ongoing
   - Opportunities to use cognitive skills are numerous and are practiced in many different settings

     [C] (Kysela 1981, Sanz 1996); [C_{dc}] (Wishart 1987)

4. It is recommended that interventions to enhance cognitive development in young children with Down syndrome include a multimodal, multimethod approach to cognitive development, including:
   - Multiple settings, as appropriate, such as the home, day care setting/school, and typical social environments
   - Multiple modalities (such as objects, pictures, sounds)
   - Multiple opportunities to practice emerging skills with different persons (parents, teachers, therapists, peers)

     [C] (Kysela 1981, Sanz 1996)

5. In some instances, it may be useful to have a primary interventionist to coordinate and provide interventions and to facilitate consistency across interventions. [D2]

6. It recommended that children with Down syndrome be exposed to activities that are appropriate for the child's chronologic age as well as the child's developmental level to stimulate cognitive development. [D2]

7. It is important to consider the need for alternative communication strategies when planning and implementing cognitive interventions. [D2]

8. It is important to use developmentally appropriate toys and objects to teach cognitive skills. [D2]

Cognitive intervention strategies

9. It is important that cognitive interventions focus on global as well as specific cognitive skills. (See age-specific recommendations, Table 19, page 162.)

   [C] (Bidder 1975, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Sanz 1996, Sloper 1986)

10. It is important to include the following in cognitive interventions:
    - Motivating tasks and reinforcement contingencies specific to the child
    - Information processing skills
    - Both short-term and long-term memory activities [D2]

11. It is important that the focus of cognitive interventions be functional with objectives related to enabling the child to function as independently as possible within his or her environment.

    [C] (Sanz 1996, Schoen 1988)

12. It is recommended that cognitive skills be taught using principles of learning theory (see Table 17, page 122).

    [C] (Bidder 1975, Bruder 1987, Kysela 1981, Schoen 1988, Sloper 1986)

Table 17: Basic Principles of Learning Theory

- Simple learning consists of the association of a stimulus and a response
- The closer together the stimulus and response occur in time, the faster the learning
- The more often a stimulus and response are paired, the stronger the association learned between them
- Repetition strengthens learned responses
- Some stimuli that occur after a behavior may increase the likelihood of the behavior occurring again; such stimuli are called positive reinforcing stimuli
- Reinforcing stimuli may be those that satisfy basic drives like food does for hunger, or satisfy the need for social acceptance, such as a smile or praise
- Some behaviors may be learned by observation and imitation

13. Because young children with Down syndrome tend to observe more than participate, it is important to encourage them:
    - To engage in spontaneous exploratory behavior
    - To approach novel experiences

    [C_{dc}] (Bradley-Johnson 1981, Lewis 1982)

14. It is important to match intervention strategies to the individual learning style of the child.

    [C] (Bidder 1975, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Sanz 1996)

Cognitive intervention for children age birth to 4 months

15. It is recommended that the teaching of cognitive skills using the principles of learning theory and the introduction of activities that will facilitate the acquisition of cognitive skills begin as soon as possible. It is important to educate parents about approaches that may help to stimulate cognitive development. These might include:
    - Having the parent move an object slowly in front of the infant's eyes so that the infant can follow the object as it moves
    - Saying the child's name often and telling the child the name or label for things in view

- Reading and singing to the child regularly

  [C_{dc}] (Ohr 1991, Ohr 1993)

16. It is recommended that individualized one-on-one intervention with the child and parent be done by someone who is experienced using the principles of learning theory with infants. [D2]

Cognitive intervention for children age 4 to12 months

17. It is recommended that development of cognitive skills using the principles of learning theory be continued. It is important to continue to educate parents about approaches that may help to stimulate cognitive development. These might include:
    - Having the parent put a pull toy or object on a string out of reach and leaving the string within the infant's reach
    - Partially hiding a toy under a towel or cloth within the infant's reach
    - Hiding a small attractive toy in an easy-to-open box
    - Showing the infant pictures with much color or contrast
    - Getting or making a mobile that moves when the infant moves in the crib

      [C] (Kysela 1981, Poulson 1988, Sloper 1986); [C_{dc}] (Ohr 1991, Ohr 1993)

18. It is important to be aware of and cautious about toy safety as children develop more independent motor skills (such as rolling, reaching, mouthing and manipulating objects, and mobility skills). In particular, be aware of:
    - Small objects (including removable items on toys or other objects) that could be swallowed or on which the child might choke
    - Strings on toys (or other objects such as window blinds) that could wrap around body parts
    - Sharp objects that could cut or puncture [D2]

Cognitive intervention for children age 12 to 24 months

19. It is recommended that development of cognitive skills using the principles of learning theory be continued. It is important to continue to educate parents about approaches that may help to stimulate cognitive development.

    [C] (Bidder 1975, Bruder 1987, Kysela 1981)

20. It is recommended that children of this age begin to be introduced to group learning experiences. This is important because children of this age begin to be able to model or imitate other children and adults.

    [C] (Schoen 1988, Sloper 1986)

21. It is recommended that the teaching of cognitive skills be increased as appropriate for the child.

    [C] (Bidder 1975, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Sanz 1996)

Cognitive intervention for children age 24 to 26 months

22. It is recommended that development of cognitive skills using the principles of learning theory be continued. It is important to continue to educate parents about approaches that may help to stimulate cognitive development.

    [C] (Bidder 1975, Bruder 1987, Kysela 1981, Schoen 1988)

23. It is important to include opportunities for interaction with other children in structured and semistructured activities. Exposure to chronologic and/or developmental age peers will help to facilitate the attainment and reinforcement of cognitive skills.

    [C] (Schoen 1988)

24. It is important to provide opportunities for generalization and exploration that enable the child to develop mastery and competencies within educational settings.

    [C] (Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993)

Monitoring progress

25. It is recommended that the child's progress (both effectiveness of the intervention and attainment of cognitive skills) be evaluated using both standardized/normed scales as well as curriculum-linked assessments and observational data.

    [C] (Bidder 1975, Bruder 1987, Connolly 1976/Connolly 1980/Connolly 1984/ Connolly 1993, Kysela 1981, Piper 1980, Sanz 1996, Schoen 1988, Sloper 1986)

26. It is important to use valid and reliable tests to measure progress of cognitive development.

    [C] (Bidder 1975, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Piper 1980, Sloper 1986)

Interventions Focused on Communication Development

Considerations for interventions focused on communication development in young children with Down syndrome are similar to those for all children with communication delays and disorders. It is important to take into account the specific levels of functioning and the needs of each individual child. Functional goals are important with realistic expectations for achievement of desired outcomes. Total communication approaches are likely to result in higher levels of success for day-to-day function.

Interventions targeting communication development in young children with Down syndrome focus on oral-motor stimulation as well as speech and language. Many children with Down syndrome have oral-motor problems that often contribute to feeding difficulties.

Most children with Down syndrome exhibit a delay in communication skills from an early age. In particular, young children with Down syndrome will usually have expressive language delays greater than expected for their receptive skills and developmental age. Expressive language delays may be compounded by speech-motor problems. Communication development in young children with Down syndrome may be further compromised because many children with Down syndrome have hearing loss.

Recommendations (Interventions Focused on Communication Development)

General approach

1. It is important to remember that no one type of speech/language intervention is the best for all young children with Down syndrome. As with all interventions, it is recommended that the type, frequency/intensity, and setting of speech/language intervention for a young child with Down syndrome be based on an assessment of the child's overall development (all domains) and the specific strengths and needs of the child and family. [D2]

2. It is recommended that some form of communication intervention (e.g., oral-motor and parent training) be initiated shortly after birth, as most children with Down syndrome exhibit a delay in communication skills from early on, including vocalization (e.g., babbling), speech, and language.

   [C] (Poulson 1988); [C_{dc}] (Cobo-Lewis 1996, Lynch 1995, Steffens 1992)

3. It is recommended that principles of learning theory be applied to interventions for communication development (see Table 17, page 122). [D2]

4. It is recommended that development of communication skills be an ongoing process that is incorporated into all activities by professionals and by the family during the course of intervention and during all activities of daily life. [D2]

Considering the primary language of the family

5. Although it is important to consider the parents' preference in determining the language used in an intervention, it is recommended that any speech/language interventions be conducted in the primary language used in the home. This is important so that:
   - Natural interaction and communication can occur between child and parent at home
   - The child can develop a firm foundation in the primary language used in the home [D2]

Considerations for the use of alternative communication strategies

6. It is important to consider the need for alternative communication strategies when planning and implementing interventions for young children with Down syndrome. [D2]

Early Intervention Policy ❖ Augmentative communication systems are considered assistive technology devices under the Early Intervention Program.

7. To facilitate development of expressive language, it is recommended that a total communication program (sign language, oral communication, and visual cues) be used. This is important as most children with Down syndrome exhibit a delay in expressive language that is not commensurate with their developmental level. When using a total communication approach, it is important that:
   - The sign language system chosen be one that can be used simultaneously with spoken English (or other language spoken in the home)

- The child receive speech/language therapy to support and enhance speech production and oral communication

  [C] (Jago 1984)

8. It is important for parents and professionals to recognize that the use of sign language does not interfere with oral language development. When sign language is included as a communication strategy, it is important that:
   - The families/caregivers and those working with the child learn the same signs and be encouraged to use them
   - The signs and the oral vocabulary being taught have practical/functional and cultural value to the family and child

     [C] (Jago 1984)

9. When planning for alternative communication strategies, such as sign language and augmentative communication systems, it is important to consider:
   - The cognitive level of the child
   - The gross and fine motor skills of the child
   - The preferences of the family [D2]

10. Amplified sound as provided through a hearing aid or other personal or group listening device may be beneficial for young children with Down syndrome who have hearing loss. [D2]

11. It is important to consider the use of amplification for children with permanent or persistent hearing loss. Amplification may take the form of hearing aids or an FM system. It is important that the child use amplification as prescribed by the audiologist. [D2]

Early Intervention Policy ❖ Personal amplification devices are considered assistive technology devices under the Early Intervention Program.

12. When the child participates in a group setting, it is important to consider the acoustic environment. The use of an FM system may be recommended for children with Down syndrome who have a hearing loss, as well as for some with normal hearing, because children with hearing loss and/or Down Syndrome often need a very favorable and highly redundant auditory signal. [D2]

Components of communication interventions

13. It is recommended that early components of intervention include:
    - Direct one-on-one interaction with parent and child
    - Observation of the parent and child with feedback provided
    - Provision of verbal and written material on how to promote oral-motor function, vocalization, and language into all daily activities

    [B] (Girolametto 1988)

14. It is recommended that parent/child intervention by a speech-language pathologist be done on an ongoing and regular basis, focusing on:
    - Stimulation of vocalization
    - Receptive and expressive language stimulation
    - Education on warning signs for hearing loss [D1]

For children age birth to 4 months

15. It is recommended that the need for facilitation of oral sensorimotor function and feeding be considered as soon as the diagnosis of Down syndrome is made and that reassessment of oral-motor function be ongoing in the early months. Oral sensorimotor function in young children with Down syndrome is often compromised because of hypotonia. It is important to ensure adequate assessment and intervention for oral-motor function because:
    - Oral sensorimotor problems usually contribute to feeding difficulties and adequate nutrition is critical for development
    - Good oral sensorimotor function promotes the development of speech skills

    [B] (Carlstedt 1996)

16. From birth to 4 months, it is recommended that speech language development be monitored by a qualified professional and that formal speech language intervention be considered if indicated by the needs of the child and family. [D1]

Early Intervention Policy ❖ The type, intensity, frequency, and duration of early intervention services are determined through the Individualized Family Service Plan (IFSP) process. All services in the IFSP must be agreed to by the parent and the Early Intervention Official. When disagreements about what should be included in the IFSP occur, parents can seek due process through mediation and/or an impartial hearing.

17. Indications for speech-language intervention during the birth to 4 month period may include, but not be limited to:
    - If the child has a hearing loss
    - If there is a feeding problem
    - If the parent indicates the need for more help/support [D2]
18. It is recommended that development of communication skills be initiated as soon as possible. It is important to educate parents about approaches that may help to stimulate communication development. This might include techniques and activities to promote:
    - Tracking auditory stimulation
    - Orienting to voices
    - Vocalizing when spoken to [D2]

For children age 4 to 12 months

19. It is recommended that development of communication skills be continued for children from age 4 to 12 months. It is important to continue to educate parents about approaches that may help to stimulate communication development. Important components of therapy during this period include:
    - The encouragement of babbling
    - Use of informal gestures to communicate (such as pointing)
    - Direct intervention with child and parents (and other caregivers) with the emphasis on educating the parents about language stimulation techniques and activities, such as:
        - Orienting to the name and voices of familiar persons
        - Making a choice between two objects
        - Looking at/pointing to pictures in a book

    [C] (Poulson 1988)

20. The use of language stimulation activities is especially important for young children with Down syndrome because it is well documented that children with Down syndrome demonstrate expressive language delays greater than expected for their receptive language skills and developmental age.

    [C_{dc}] (Mahoney 1981, Mundy 1988)

21. It is important to provide ongoing oral-motor activities to promote the development of adequate strength, stability, and oral-motor movement for feeding and speech production. This is important during this period because of the transition from liquids to solids, nipple to cup, etc., and the emergence of canonical babbling. [D2]

For children age 12 to 24 months

22. It is recommended that the child continue to receive speech/language therapy appropriate for the individual needs of the child and that parents continue to receive education in language stimulation techniques and activities. This might include techniques and activities to promote:
    - Understanding basic concepts
    - Following a one-step request
    - Pointing to body parts
    - Saying or signing two-word phrases
    - Pointing to objects upon request
    - Signing or naming familiar objects

    [C] (Jago 1984)

23. It is likely to be beneficial to increase the frequency and intensity of the communication interventions from 12 to 24 months because:
    - This is the time when speech and language skills typically accelerate, and there may be a need to facilitate this
    - The divergence between the developmental progress of children with Down syndrome and typically developing children of the same age becomes greater

    [C_{dc}] (Carr 1970, Caselli 1998)

24. It is recommended that oral-motor intervention be continued, as needed, to address the muscle-based issues that continue to affect the child's oral expressive output. [D2]

25. It is recommended that the child have the opportunity for linguistic interaction with other children. This may take the form of playgroups, day care, therapeutic groups, etc. This may help to stimulate and generalize language skills. [D2]

For children age 24 to 36 months

26. It is recommended that the child continue to receive speech/language therapy appropriate for the individual needs of the child and that parents continue to receive education in language stimulation techniques.

    [B] (Girolametto 1988, Jago 1984)

27. During this time period, it may be beneficial for the child to participate in a structured group setting with other similar age peers in order to:
    - Enhance language skills
    - Facilitate communication success
    - Provide opportunities for linguistic interaction with peers [D2]

28. It is important that speech/language interventions during this period target:
    - Increasing vocabulary (oral and signs)
    - Increasing receptive and expressive language skills
    - Improving motor speech production (including appropriate oral-motor activities to promote speech production and respiratory control) [D2]

Interventions Focused on Motor Development

Motor development is the process of how we learn to sit, stand, move in space or place and use our hands to work, take care of ourselves, and play. Motor development depends on how sensory input is processed in the brain to result in a purposeful movement. Gross motor development refers to the ability to move the large muscle groups of the body (neck, trunk, and limbs), while fine motor development refers to the use of the hands and fingers. Because many children with Down syndrome are hypotonic and have other problems with postural control, this is an important focus of early motor intervention for children with Down syndrome.

Neurodevelopmental treatment (NDT)

Neuromotor therapies, such as neurodevelopmental treatment (NDT), are commonly used as a component of motor interventions for children with movement dysfunction. The primary goal of NDT is to prepare the child for specific functional activities. This is achieved by inhibiting dysfunctional

movement patterns and facilitating more efficient movement patterns. Specific handling and positioning techniques are used to modify the sensory input to the child to elicit functional, goal-oriented movements. These methods are taught to parents to use in the child's daily activities. Principles of motor development, motor control, and motor learning are used to enhance functional outcomes. Although NDT approaches are widely used as a component of various therapy programs, scientific studies have not been done that demonstrate the benefits of these therapies in young children with Down syndrome.

Recommendations (Interventions Focused on Motor Development)

General approach

1. It is important to remember that there is not one specific motor intervention technique or theoretical model that is effective with all children. As with all interventions, it is recommended that the type, frequency/intensity, and setting of motor intervention be based on an assessment of the child's overall developmental level (all domains) and the specific strengths and needs of the child and family. [D2]
2. It is recommended that development of motor skills be an ongoing process that is incorporated into all activities by professionals and by the family during the course of intervention and during all activities of daily life. [D2]
3. It is recommended that principles of learning theory be applied to interventions for motor development (see Table 17, page 122). [D2]
4. It is recommended that motor interventions use techniques that:
   - Help the child learn to problem solve and participate in planning, initiating, and performing movement
   - Facilitate movement experiences for which the child is ready but may not seek out alone
   - Use varied types of stimuli to elicit movements according to the child's response [D2]
5. It is recommended that motor interventions be provided in a variety of settings that include both indoor and outdoor environments. [D2]
6. It is important to consider the child's approach to motor learning when planning and implementing motor interventions. [D2]

Including the parent and primary caregivers

7. It is important to teach parents and primary caregivers appropriate play activities to enhance appropriate motor development. [D1]

8. It is important to instruct parents and other caregivers in appropriate carrying and handling techniques. For example:
   - It may be important for some children to be carried with their legs together rather than splayed over the hip
   - It may be important to modify (or not use) backpack- or "Snugli"-type carriers so the child's legs stay together when carried [D2]

9. It is important to help parents and primary caregivers understand the child's approach to motor learning. [D1]

Considering the child's health status

10. It is important to obtain all relevant information about the child's health status and associated health conditions (such as cardiac or respiratory problems) that may affect motor activities. [D2]

11. It is important to monitor the child's health status and tolerance for motor activities throughout the intervention. [D2]

Using adaptive equipment and assistive technology

12. It is important that the use of any assistive devices or adaptive equipment be developmentally appropriate for the child. [D2]

13. It is important to consider the need for adaptive equipment that will assist in maintaining postural alignment and promote sitting, standing, and mobility for young children with Down syndrome, for example, sidelyers, standing devices, seating systems, and adapted tricycles. [D2]

14. It is important to consider the need for assistive devices that will promote independent upright forward progression for mobility for young children with Down syndrome, such as forward walkers, postural control walkers, push toys, and ride-on toys. [D2]

15. The use of orthotics or lower extremity splints may be beneficial for some young children with Down syndrome for maintaining proper alignment in standing and walking. [D2]

Early Intervention Policy ❖ Assistive technology devices may be provided to children eligible for the Early Intervention Program when these devices are necessary to increase, maintain, or improve the functional capabilities of an infant or toddler in one or more of the following areas of development: physical development, communication development, cognitive development, social/emotional development, or adaptive development. Assistive technology devices are defined as "any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized that is used to increase, maintain, or improve the functional capabilities of children with disabilities."

Intervention approaches not recommended

16. Caution should be exerted when considering the use of activities that involve hyperflexion, hyperextension, and rapid rotary movements of the neck. These activities are not recommended for young children with Down syndrome because of the risk for atlantoaxial instability (dislocation of the first two cervical vertebrae). Atlantoaxial instability cannot be ruled out until x-rays can be completed at about the age of 3 years. [D2]

17. Use of rotary movement (vestibular stimulation) was not found to be effective in improving motor skills in young children with Down syndrome. However, as for any preschool child, incorporating sensory activities such as movement into other therapeutic techniques may be beneficial to overall development. Varied sensory activities may be useful if they support the attainment of specific goals.

    [A] (Harris 1981/Harris 1981A, Lydic 1985)

18. The use of baby walkers, "exersaucers," "jolly jumpers," and other similar equipment is not indicated for children with Down syndrome. These items encourage stereotypic movement patterns that tend to delay motor development. Also, children with Down syndrome may lack the joint stability to maintain good alignment while using this kind of equipment. [D1]

19. The use of weighted vests or weights must be carefully monitored so as not to facilitate the development of harmful postures. Children with Down syndrome may lack the trunk, arm, or leg stability to maintain proper alignment with the addition of supplemental weight. [D1]

20. Range of motion exercises are not recommended for young children with Down syndrome unless there is a specific limitation in joint mobility. [D1]

21. The guideline panel found no evidence to support the use of treadmills for children with Down syndrome. [D1]

For children age birth to 4 months

22. It is important not to wait until demonstrated lags in motor milestones have occurred to begin motor intervention for children with Down syndrome.

    [C_{dc}] (Haley 1986, Haley 1987, Rast 1985, Ulrich 1995)

23. It is recommended that intervention for motor development begin within the first month. It is important to start this early to:
    - Prevent compensatory movement patterns that may interfere with subsequent motor development
    - Prevent the development of deformities secondary to persistent atypical postures
    - Provide education and support to parents (e.g., to teach positioning and handling)

    [C_{dc}] (Haley 1986, Haley 1987, Rast 1985)

24. It is recommended that motor intervention for very young children with Down syndrome (age birth to 4 months) focus on development of postural control (ability to control head and trunk). Development of good postural control will help to facilitate future development of specific motor skills.

    [C_{dc}] (Haley 1987, Rast 1985, Ulrich 1995)

For children age 4 to 12 months

25. It is important to continue motor interventions related to postural control as the child develops during the first year. Appropriate postural control for weight bearing is especially important in young children with Down syndrome because of their tendency for joint instability, low muscle tone, hyperextension, and ligimentous laxity. Poor postural control as an infant may lead to the use of compensatory patterns that result in future problems with motor development. For children age 4 to 12 months, it is important that motor interventions include:
    - Development of postural control for head and upper trunk righting and upper extremity weight bearing in prone position (lying on stomach)
    - Development of the ability to move against gravity to bring hands to midline and hands to mouth
    - Development of trunk and head control for proper alignment in sitting

- Development of postural control, scapular stability, and upper extremity strength to support fine motor control
- Development of varied movements in the legs to support the development of standing
- Development of transitional movements (rolling, pivoting prone, belly crawling, getting in and out of sitting, etc.)

  [C_{dc}] (Haley 1986, Haley 1987, Rast 1985)

26. It is recommended that a specific focus on fine motor interventions begin when the child is approximately 6 months old. Important components of fine motor interventions include:
    - Shoulder stability when on stomach and when reaching
    - Hand-to-mouth movements
    - Development of hand muscles, especially the arches of the hands
    - Digital grasp
    - Transfer of objects from hand to hand
    - Isolated use of index finger [D1]
27. The use of standardized or norm-referenced motor development scales, such as the Peabody Developmental Motor Scales, may be useful for assessing the development of functional motor skills of young children with Down syndrome. (See Table 10, page 74, for a list of additional motor development tests.)

    [A] (Harris 1981/Harris 1981A, Lydic 1985)
28. Resistive activities (strength training) may be beneficial to increase strength in young children with Down syndrome after the age of 4 months. This may be important in some young children with Down syndrome to strengthen muscles needed for joint stability and for postural reactions. Resistive activities may include:
    - Gentle, graded manual resistance
    - Playing with developmentally appropriate toys of varying weights
    - Lifting, carrying, and pushing toys [D1]

For children age 12 to 24 months

29. It is recommended that intervention for development of fine motor skills be continued for children with Down syndrome age 12 to 24 months. Important components of intervention include:

- Prehension patterns
- Grip strength
- Shoulder stability
- Finger and thumb control
- In-hand manipulation
- Bilateral coordination
- Release of objects such as putting blocks in a container
- Eye-hand coordination such as putting pegs in a board
- Refinement of grasp patterns [D1]

30. It is recommended that intervention for the development of gross motor skills with a focus on improving the use of muscular control, posture, and movement rather than the use of compensatory positions, be continued in children with Down syndrome age 12 to 24 months. Components to be addressed include:
    - Development of creeping on hands and knees
    - Development of sufficient postural control to move in and out of sitting in varied patterns
    - Development of pull-to-stand, standing, and cruising
    - Balance and coordination of trunk muscles
    - Use of coordinated control in hips, knee, ankles, and feet
    - Use of varied movements for transition

    [C_{dc}] (Cobo-Lewis 1996, Haley 1986, Haley 1987, Ulrich 1995, Ulrich 1997)

After age 24 months

31. It is recommended that intervention for development of fine motor skills be continued in children with Down syndrome after the age of 24 months. Important components of intervention to add include:
    - Use of writing utensils
    - Turning knobs and lids
    - Rotating forearms [D1]

32. It is recommended that intervention for the development of gross motor skills be continued for children with Down syndrome after the age of 24 months. It is important to include:
    - Development of independent walking

- Appropriate adaptive equipment and/or toys to provide opportunities for independent upright mobility for children not yet walking
- Development of stair climbing
- Development of higher level motor skills [D1]

Interventions Focused on Social Development

Interventions targeting social development focus on social attention, social interactions, attachment, and play. A major component of interventions in social interactions consists of helping parents to interact with a child who, compared with typically developing children, takes less initiative, responds and initiates interactions in a more unpredictable manner, often shows less affect (emotional expression), and gives social and communicative cues that are less readable to others.

Recommendations (Interventions Focused on Social Development)

General approach

1. It is important to remember that there is not one specific intervention approach to facilitate social development that is effective with all children. As with all interventions, it is recommended that the type, frequency/intensity, and setting of the intervention be based on an assessment of the child's overall developmental level (all domains) and the specific strengths and needs of the child and family. [D2]

2. It is recommended that development of social skills be an ongoing process that is incorporated into all activities by professionals and by the family during the course of intervention and during all activities of daily life. [D2]

3. It is recommended that principles of learning theory be applied to interventions for development of social skills (Table 17, page 122). [D2]

4. When choosing tasks to facilitate social development for young children with Down syndrome, it is important to consider both developmental and chronological age.

   [C] (Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993)

5. It is important to help parents gain an understanding of their child's development in order for them to have appropriate expectations. Often parents need to be educated to raise their expectations about the child's social development. [D2]

Specific approaches for social development

6. It is important for parents and others interacting with young children with Down syndrome to include requests for attention (to have the child's attention) when requesting actions from the child and to positively reinforce appropriate responses to those requests.

   [C_{dc}] (Bressanutti 1992, Landry 1994, Mahoney 1990)

7. Because children with Down syndrome often have an increased interest in attending to faces, which may interfere with learning new play skills, it is important to include opportunities for exploratory play and object manipulation.

   [C_{dc}] (Crown 1992, Gunn 1982, Kasari 1990, Kasari 1995, Landry 1990)

8. For those children who tend to focus more on faces, it is important to encourage them to interact with the physical environment (e.g., toys) in groups with other children. This may facilitate play skills and enhance social skills. [D1]

9. When working with young children with Down syndrome, it is important to remember that the child may be more responsive to instructions that are directive (specific) rather than to instructions that are suggestive (not specific).

   [C_{dc}] (Cielinski 1995, Landry 1994, Mahoney 1990, Tannock 1988)

10. Activities that include music may be useful to enhance social skills such as interaction, attention, and participation.

    [C_{dc}] (Glenn 1981, Ruskin 1994)

11. It is important to provide opportunities for young children with Down syndrome to be exposed to many social situations in different settings in order to:
    - Stimulate and selectively reinforce appropriate affective responses
    - Facilitate language development
    - Improve peer interactions
    - Promote generalization of affective responses [D1]

12. To increase the child's level of sustained engagement during planned activities, it is helpful to change stimuli frequently (e.g., change the toy or object used during the interaction).

    [C_{dc}] (Lewis 1982, MacTurk 1985)

13. It is important to teach and encourage children with Down syndrome to initiate social interactions. Approaches for doing this include:
    - Selective reinforcement
    - Peer modeling
    - Adult modeling

    [B] (Girolametto 1988, Poulson 1988, Sloper 1986)

14. It is important to provide opportunities for the child with Down syndrome to initiate activities. It is also important to provide opportunities for the child to participate in activities in which the parent or professional can follow the child's lead.

    [B] (Girolametto 1988, Kysela 1981); [C_{dc}] (Bressanutti 1992, Landry 1989, Landry 1990, Landry 1994, Ruskin 1994)

Interventions Focused on Adaptive/Self-Help Skills

Interventions focused on helping the child to develop adaptive self-help/self-care skills are often the most important for families. These skills allow the child to function more independently. Adaptive/self-help skills, often referred to as activities of daily living, include dressing/grooming, feeding, and toileting.

Recommendations (Interventions Focused on Adaptive/Self-Help Skills)

General approach

1. It is important to remember that there is not one specific intervention approach to facilitate development of adaptive/self-help skills that is effective with all children. As with all interventions, it is recommended that the type, frequency/intensity, and setting of the intervention be based on an assessment of the child's overall developmental level and the specific strengths and needs of the child and family. [D2]

2. It is recommended that development of adaptive/self-help skills be an ongoing process that is incorporated into all activities by professionals and by the family during the course of intervention and during all activities of daily life. [D2]

3. It is recommended that principles of learning theory be applied to interventions for teaching adaptive/self-help skills (Table 17, page 122). [D2]

4. When choosing tasks to facilitate development of adaptive/self-help skills for young children with Down syndrome, it is important to consider both

developmental and chronologic age. It is also important to remember that development of adaptive/self-help skills will depend on the child's cognitive and motor skills. [D2]

5. Consistency in approach to teaching self-care is essential. It is important to recognize that if different approaches are used, they may be confusing to the child and hinder learning. [D2]

6. It is important to remember that while the order in which self-help skills are learned is similar in both typically developing children and children with Down syndrome, development of self-help skills is usually delayed in children with Down syndrome. It is also important to remember that children with Down syndrome may need more repetition in learning self-care tasks than typically developing children.

   [C_{dc}] (Wishart 1987)

7. It is recommended that adequate support be provided to optimize the motor control the child has for self-care activities. For example, for self-dressing, the child may need to sit in a chair with arms if he/she does not have adequate postural stability or awareness of position in space. [D2]

8. As for any child, it is important to make sure that the child has developmentally appropriate opportunities for self-care that will facilitate both independence and progression of skills, such as provide clothing without fasteners until the child has mastered buttoning, zipping, etc. [D2]

Feeding

9. It is recommended that in order to help the child with Down syndrome learn to feed himself or herself, mealtimes be made distinct (for example, at a table and without other distractions such as the television). [D2]

10. Consistency in mealtime and premealtime routines and the opportunity to learn from observing others at mealtime can help to facilitate the learning process. [D2]

11. It is important to provide adequate support and positioning for the child with Down syndrome during meals. Establishment of proper positioning early will facilitate the child's learning to feed him or herself when ready. [D2]

12. It is important to use utensils, dishes, and cups that are developmentally appropriate for the child's motor and cognitive abilities. For some children,

it may be appropriate to consider the need for specific adaptive equipment to facilitate self-feeding. [D2]

13. When the child is learning self-feeding, it may be helpful to:
    - Use a spoon with a thicker curved handle to allow the child to have better control of the spoon
    - Use a cup with two handles to encourage a more symmetrical posture when drinking
    - Avoid or limit use of cups with spouted lids, as these may interfere with development of lip closure [D2]

Dressing

14. It is important to encourage children with Down syndrome to help with their own dressing when they appear to be ready. When teaching self-dressing, it is important to use clothing that is developmentally appropriate for the child's motor and cognitive abilities. [D2]

15. It is important to remember that children are usually independent in removing clothing before they are independent in putting clothes on. [D2]

16. It is important to provide adequate support and positioning to aid the child when dressing. Establishment of proper positioning and use of appropriate supports early will facilitate the child's self-dressing development when the child is ready. [D2]

17. As for any child, there are various techniques that can be used to facilitate teaching of self-dressing skills:
    - Making simple modifications to clothing to increase independence (For example, use of Velcro instead of buttons, zippers, and ties, or attaching an easy-to-grip object to a zipper pull.)
    - Dressing in loose, easy to pull-on/take-off clothing
    - Modifying methods of dressing to make it easier for children to learn (For example, teaching children to put both arms in the coat and then flip it up and over the head.)
    - Using a backwards chaining approach (For example, the caregiver completes the initial steps, and then teaches the child the last step. When the child has mastered the final step, the child is taught the final two steps. Add the steps expected of the child until the task is mastered.) [D2]

Toilet training

18. As for all children, it is important that the child be developmentally ready to begin toilet training. Development of motor and cognitive skills is an important component of successful toilet training. Toilet training is usually more successful when the child's motor system has matured adequately. When the child demonstrates some regularity in elimination, it is often an indication of increased bladder and bowel control. [D2]

19. It is important to allow the child to become familiar with the bathroom and toilet before toilet training is attempted. When initiating toilet training, it is usually helpful to be consistent about which bathroom is used if there is more than one bathroom in the house. [D2]

20. It is important that the potty seat or toilet is of an appropriate size and configuration to support the child and allow for as much independent mobility as possible when getting on and off of the seat. [D2]

21. It is important to recognize that children with Down syndrome often have associated conditions that may make toilet training more challenging, such as low muscle tone (hypotonia), which might make bladder control more difficult. [D2]

SPECIFIC INTERVENTION APPROACHES

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

The recommendations for specific intervention approaches for young children with Down syndrome include a combination of both evidence-based and panel consensus recommendations. The evidence-based recommendations are derived from the scientific literature reviewed for this section of the guideline. The consensus recommendations generally relate to approaches that are not typically evaluated in controlled scientific studies having to do with the efficacy of specific intervention methods.

Behavioral and Educational Approaches

Behavioral and educational approaches are programs, strategies, procedures, and techniques based on general learning and behavioral principles. A systematic behavioral approach is sometimes referred to as applied behavioral analysis

(ABA). However, many other educational interventions for young children with Down syndrome are based on somewhat similar behavioral principles derived from a vast body of research on the learning process. Behavioral and educational intervention programs for young children are reviewed together because they are based on common behavioral principles and share common elements.

Basic principles of behavioral and educational intervention approaches

Behavioral and educational interventions include specific approaches to help individuals acquire or change behaviors. While all behavioral and educational interventions have some basic similarities, specific techniques vary in several ways. Some techniques focus on the antecedent conditions (i.e., procedures implemented before a target behavior occurs). Other techniques focus on the consequence of a behavior (i.e., procedures implemented following a behavior). Still other techniques involve skill development and procedures to teach alternative, more adaptive behaviors. These strategies often consist of building complex behaviors from simple ones using techniques such as shaping and successive approximations. The intervention strategies and goals will change as the child makes progress (or does not make progress) or when there is a change in the environment.

Naturalistic and directive approaches

Behavioral and educational interventions can vary according to whether they are more directive or more naturalistic in their approach. In directive approaches, the teacher or therapist structures the environment and specifies the antecedent stimuli and consequences (which may not necessarily flow logically from the child's current activities or interests). In contrast, naturalistic approaches attempt to make the intervention setting similar to the child's usual environment and also attempt to use antecedent stimuli and consequences (such as reinforcers) that are related to the child's usual environment and everyday activities. In practice, few interventions for children with Down syndrome are either totally directive or totally naturalistic. Instead, most interventions fall somewhere on a continuum between these two approaches, incorporating some directive and some naturalistic elements.

Recommendations (Behavioral and Educational Approaches)

General approach

1. It is recommended that intervention approaches for young children with Down syndrome include aspects of behavioral techniques. Important concepts include:

- Individualizing the strategies to the child (there is no single approach that is appropriate for all children)
- Use of reinforcing stimuli that are appropriate to the individual child
- Use of consistent reinforcing stimuli (i.e., continuous mass-trial learning) to facilitate learning a new task

  [C] (Bidder 1975, Bruder 1987, Kysela 1981, Poulson 1988, Schoen 1988, Sloper 1986)

2. It is recommended that parents be educated in the use of reinforcement strategies to facilitate development of cognitive, social, linguistic, educational, and self-help skills.

   [B] (Bidder 1975, Bruder 1987, Girolametto 1988, Jago 1984, Kysela 1981, Poulson 1988, Purdy 1987, Sanz 1996, Sloper 1986)

Using behavioral techniques

3. When using reinforcing stimuli, it is important to recognize that:
   - There are several types of potential reinforcing stimuli, for example:
     - Sensory (such as music)
     - Edible (such as a favorite snack)
     - Social (such as verbal praise)
   - A reinforcer assessment is helpful to identify which items will serve as reinforcers for a particular child
   - It may be helpful to vary the reinforcers used

     [C] (Poulson 1988); [C_{dc}] (Ohr 1991, Ohr 1993)

4. It is important to remember that children with Down syndrome may require multiple trials to learn most tasks.

   [C_{dc}] (Wishart 1987)

5. It is recommended that complex skills and tasks be introduced sequentially by breaking them down into component parts that are easier to learn (i.e., teaching new tasks step-by-step).

   [C] (Bruder 1987, Schoen 1988, Sloper 1986)

Selecting specific techniques

6. It is recommended that operant conditioning techniques (waiting for the response and then providing positive reinforcement) be used to teach new behaviors to young children with Down syndrome.

   [C] (Poulson 1988); [C_{dc}] (Ohr 1991, Ohr 1993)

7. It is important to recognize that highly motivating tasks are more easily learned than are less desirable tasks. [D2]

8. It is important to use visually distinctive stimuli because children with Down syndrome attend more to visual than to auditory stimuli. Using visual teaching methods is an effective technique for introducing new concepts when teaching young children with Down syndrome. [D1]

9. It is important to use behavioral techniques and strategies that facilitate generalization of skills to other environments. These may include multiple learning situations using multiple teachers, therapists, parents, and caregivers in multiple settings. For children with Down syndrome, this may take longer and may require more repeated attempts.

   [C] (Kysela 1981, Sanz 1996)

Selecting targets for intervention

10. It is important to teach concepts and skills that are:
    - Related to the everyday life of the child
    - Related to the child's ability to integrate into the child's natural environment
    - Relevant to the child's ability to integrate into society
    - Consistent with the parents' priorities for their child's development

    [C] (Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981, Sanz 1996, Schoen 1988)

Early Intervention Policy ❖ Under the Individuals with Disabilities Education Act and New York State Public Health Law, early intervention services must be provided in natural environments to the maximum extent appropriate to the needs of the child. "Natural environments" means settings that are natural or normal for the child's age peers who have no disabilities.

11. It is important to consider the specific requests of the family when learning objectives are being developed for a child. [D2]

12. It is important to recognize that for children with Down syndrome, basic concepts (such as "in," "on," and color discrimination) need to be specifically taught. [C_{dc}] (Harris 1983)

Assessing progress and modifying the intervention as needed

13. When assessing a child's progress, it is important to:
    - Monitor the emergence of the skill using observable and measurable behaviors
    - Provide multiple learning trials until the child has reached criteria of mastery for the skill
    - Test for retention of learned skills

    [C] (Schoen 1988, Sloper 1986)

14. It is important to initiate an analysis of the task, educational interventions, and reinforcement schedule when the child fails to achieve the educational, social, linguistic, and adaptive skills being taught. [D1]

Dealing with maladaptive behaviors

15. Maladaptive behaviors (e.g., temper tantrums, running away, noncompliance) are usually learned behaviors. It is recommended that interventions for these challenging behaviors be determined using a functional behavioral assessment and behavioral intervention plans. Examples may include:
    - Ignoring the behavior
    - Differential reinforcement of other behaviors
    - Distracting/redirecting
    - Teaching other behaviors [D2]

16. It is important to determine if there are triggers for maladaptive behaviors that can be addressed as part of the intervention plan. For example, some maladaptive behaviors may be related to hyperresponsivity to certain sensory stimuli (e.g., a child may not allow a toothbrush in his mouth because of oral hyperresponsivity). [D2]

17. It is important to remember that maladaptive behaviors may be a child's way of communicating that a task or situation is too difficult, uncomfortable, or stressful for the child. [D2]

Other Intervention Approaches

There are many different types of intervention approaches and programs that might be considered for a young child with Down syndrome. In addition to the more standard or traditional developmental therapies (such as physical and occupational therapy, speech/language therapy), there is also a diverse collection

of therapeutic models (such as sensory integration, aquatic therapy, hippotherapy, and music therapy) that are often used in conjunction with or as a part of standard therapy programs. Some of these approaches are also sometimes used as separate, distinct programs as “alternative” (or “nonstandard”) approaches. These approaches vary greatly in how commonly they are used, the time commitment required (intensity), cost, availability, and potential benefits and harms. Some of these approaches are also considered controversial.

Although these other intervention approaches are sometimes used for children with Down syndrome, often in conjunction with standard therapies, the efficacy of these approaches is generally not supported by rigorous scientific studies. While scientific evidence is generally not available to support the efficacy of these approaches, some alternative therapies may provide other benefits to the child and family, such as opportunities for physical activity and socialization, when used in addition to the child’s primary therapy.

In today’s world of instant information through the Internet, parents and family members are likely to seek information about their child’s disability, and they are likely to find many sources of information about alternative intervention options, including tempting claims that a particular intervention will lead to a dramatic improvement in the child’s condition. Parents who want the best for their child need to understand how to evaluate this information, and professionals who want to work effectively with the parents need to understand how to help them make intervention decisions, especially when they are considering an unproven or controversial approach.

It is not possible to include information and recommendations about all of the other programs and approaches that might be promoted for young children with Down syndrome. There will always be new theories and techniques, and new iterations of old methods, especially for conditions for which there is no known cure.

Regardless of the specific intervention being considered for a particular child, the decision-making process is the same. Therefore, the focus of this section is the general decision-making process for considering other intervention approaches. Information is provided about a few of the more common approaches that are generally considered “alternative” or “nonstandard” but are sometimes suggested for young children with Down syndrome.

Other more health-related “alternative” interventions (such as megavitamins and fetal-cell therapy) are discussed later in this chapter (Health-Related Interventions, pages 154 to 162).

Sensory integration therapy

Sensory integration (SI) therapy is based on an approach that evaluates children for sensory processing disturbances and provides them with the appropriate sensory stimulation. Sensory experiences involving touch, controlled movement, balance, or passive sensory input are provided to the child to elicit adaptive responses to these stimuli. The sensory experiences used generally include goal-oriented play using activities that offer opportunities for enhanced sensory intake. The stated goal of sensory integration therapy is to facilitate the development of the nervous system's ability to process sensory input. Scientific studies were not found to support the efficacy of sensory integration as a separate therapy approach.

Music therapy and art therapy

While various music and art activities are often included within the context of many intervention approaches for children with Down syndrome, there are also some who advocate for separate, discrete intervention approaches referred to as "music therapy" and "art therapy." Proponents of these therapies (used as a separate discrete therapy) suggest they may lead to improvements in social interaction and language development (music therapy) and improved motor and cognitive skills (art therapy). Scientific studies were not found to support the efficacy of either of these therapies (as a separate therapy approach) in children with Down syndrome.

Early Intervention Policy ❖ Music therapy and art therapy are not reimbursable services under the New York State Early Intervention Program.

Conductive education

Conductive education is an educational approach focused primarily on motor function. This approach, developed in Budapest, Hungary, in the 1940s, is based on the theory that abnormal motor patterns ("dysfunction") can be transformed into functional motor patterns ("orthofunction") by intensive "training" to develop alternate neural pathways.

Each child has a "conductor" who is specifically trained in the technique of conductive education. It is the responsibility of the conductor to work with the child throughout the day to produce favorable conditions that facilitate the child's daily tasks. Additional assistants employ a "hands-on" technique with

more impaired children. Daily tasks (such as sitting and walking) are broken down to their simpler components. These components are then incorporated into a rhyme or song that the child repeats to self-motivate and anticipate the task before him. In the United States, many conductive education programs use only selective principles of this method.

Conductive education has not been demonstrated in controlled scientific studies to have efficacy for improving motor development in young children with Down syndrome. For children with motor impairments, there is some concern that, unless children are closely monitored, there may be some risk for developing persistent pathological motor patterns.

Therapeutic horseback riding (hippotherapy)

Therapeutic horseback riding (hippotherapy) is sometimes used as an intervention for children with Down syndrome, although perhaps not as often for children under the age of 3 years. The major aims of therapeutic riding include 1) mobilization of the pelvis, lumbar spine, and hip joints; 2) activation of head and trunk musculature; 3) development of head and trunk postural control; and 4) development of balance reactions in the trunk.

The therapist places the child in various positions on the horse (such as prone, side lying, side sitting, or sitting). A soft pad is used rather than a saddle so that the child can experience the warmth and movement of the walking horse. Sometimes the therapist and child will ride together so the therapist can facilitate the movement. The horse is usually led at a walking pace by a skilled equestrian to ensure safety.

Scientific studies were not found to support the efficacy of hippotherapy for improving motor development in young children with Down syndrome. For young children with Down syndrome, as with all children in this age group, the potential for injury that may result from horseback riding needs to be considered in the decision about whether to use this intervention approach.

Recommendations (Other Intervention Approaches)

General approach for nonstandard or alternative therapies

1. It is important for professionals to ensure that families have access to standard services and are actively involved in all intervention decisions. [D2]
2. It is important to have a systematic method to facilitate a decision-making process in which parents and professionals work together to make an informed decision based on the overall goals for the child and family before initiating any intervention. [D2]
3. It is important to recognize that if parents do not receive information about alternative therapies directly from health and educational professionals, they will obtain that information from the proponents of those therapies and/or other parents, and this information may be limited and/or biased and/or incorrect. [D2]
4. It is recommended that:
   - Professionals be knowledgeable about alternative interventions, including the proposed benefits, the possible harms, and costs
   - Professionals be open to discussing alternative interventions and schedule adequate time for this as part of the initial management plan and for parents to ask to questions about such interventions
   - Professionals who discuss alternative interventions with families make sure that the discussion is informative while making it clear that the discussion is not an endorsement of the intervention [D2]
5. When considering any intervention, it is recommended that the questions from Table 18 be included in the decision-making process. [D2]
6. If parents choose to pursue an alternative intervention, it is recommended that the intervention be coordinated with other interventions the child is receiving to avoid any potential conflicts in establishing and achieving goals for the interventions. [D2]

Table 18: Questions to Ask Regarding Specific Interventions

- What do I want to accomplish with this intervention? Is the intervention likely to accomplish this?
- Are there any potentially harmful techniques or side effects associated with this

Table 18: Questions to Ask Regarding Specific Interventions

intervention?

- What positive effects of the intervention would I hope to see?
- Has the intervention been validated scientifically (with carefully designed research studies) for young children with Down syndrome?
- Can this intervention be integrated into my child's current program?
- What is the time commitment? Is it realistic?
- What are the pros and cons of this intervention? What do other parents say about it (pro and con)?
- What claims do proponents make about this intervention? (Claims of dramatic improvement are probably a "red flag.")
- Does the provider of the intervention have knowledge about the medical and developmental issues associated with Down syndrome?
- Does the provider of the intervention have experience working with young children with Down syndrome?
- What do my pediatrician and other professionals involved with my child think about the intervention's appropriateness?

Adapted from: Nickel 1996
(Continued from previous page)

7. It is important for professionals to remain actively involved and available to parents to discuss the effects of any intervention that parents may choose. It is important that the professional be supportive and helpful in the decision-making process and in ongoing monitoring of the effects of the interventions. [D2]

8. It is essential that all providers, including providers of alternative interventions, who work with young children with Down syndrome:
   - Have experience working with young children with Down syndrome
   - Understand the developmental and medical problems commonly associated with Down syndrome and the implications for the specific intervention provided (such as concerns about hypermobility of hips during therapeutic horseback riding)
   - Receive relevant information about the child's health status and associated health conditions, such as cardiac or respiratory problems, which may affect the way that the intervention is implemented

- Understand the importance of monitoring the child's health status and tolerance for motor activities during the intervention [D2]

9. It is important that an intervention plan be developed for each intervention and that this plan:
   - Be compatible with the overall intervention goals for the child and family
   - Set defined intervention goals and objective outcome measures
   - Provide for baseline and ongoing assessment of the child's progress
   - Provide for appropriate modification of the intervention based on the child's progress [D2]

Early Intervention Policy ❖ The Individualized Family Service Plan (IFSP) must be in writing and have required components as specified in program regulations, 10 NYCRR Section 69-4.11(10). See Appendix D for Early Intervention Program regulations.

10. It may be useful to inform parents about the placebo effect and the importance of a controlled, blind research trial to establish an intervention's effectiveness. [D2]

11. When using alternative interventions, it may be useful to monitor progress by providing the intervention for one month, stopping for one month, providing the intervention again for one month, and stopping again to evaluate the effect of the intervention. [D2]

Early Intervention Policy ❖ Music therapy and art therapy are not reimbursable services under the New York State Early Intervention Program. For some interventions, such as sensory integration, aquatic therapy, and hippotherapy, the Early Intervention Program may reimburse for the cost of *qualified personnel*, such as a physical therapist, as provided for in the Individualized Family Service Plan (IFSP), but does not reimburse for other program expenses (such as fees for the pool or the horse). Qualified personnel are listed in Appendix D.

Sensory integration, music therapy, art therapy, and therapeutic horseback riding

12. It is important to understand that while therapies such as sensory integration, music therapy, art therapy, and therapeutic horseback riding are not likely to be physically harmful (when implemented by knowledgeable and experienced providers) and may have some benefits (such as physical activity, social interaction, or generalization of developmental skills), no adequate research evidence was found by the guideline panel about the efficacy of these as discrete interventions in young children with Down syndrome. However, just as for any child, incorporating sensory activities (movement, music, art) into other therapeutic techniques may be beneficial to overall development. Varied sensory activities may be useful if they support the attainment of specific goals. [D1]

Conductive education

13. It is important to recognize that:
    - The conductive education approach can be time intensive for both professionals and parents, and may take time away from other therapies that might be appropriate and effective for the child
    - No evidence was found by the guideline panel about the efficacy of the conductive education approach in young children with Down syndrome [D1]

HEALTH-RELATED INTERVENTIONS

Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited
[$_{dc}$] = Developmental Characteristics study
[D1] = Literature searched but no evidence [D2] = Literature not reviewed

General Considerations About Health-Related Interventions

The specific health-related interventions for any particular young child with Down syndrome will depend on the results of the child's health evaluation (see page 85). Many medical conditions occur more commonly in children with Down syndrome than in typically developing children. Some of these conditions are listed in Table 15 (page 101). It was considered beyond the scope of this guideline to evaluate the efficacy of interventions for most of these medical conditions. However, a few specific health-related interventions are

discussed, including interventions focusing on growth and nutrition, oral-motor/feeding issues, and hearing and vision.

Some interventions available to families of children with Down syndrome are considered "alternative," experimental, or controversial. Many of the alternative interventions that are promoted to these families might be regarded as health-related (such as megavitamins and use of piracetam). The general approach for use of alternative interventions was discussed previously in this chapter (Other Intervention Approaches, page 147). Some of the specific health-related alternative therapies are discussed later in this section.

Recommendations (General Considerations About Health-Related Interventions)

General approach to health interventions

1. It is recommended that children with Down syndrome receive the same general routine preventive health care as typically developing children. In addition, it is recommended that physicians follow the general outline designed by the American Academy of Pediatrics Committee on Genetics, in providing medical care for children with Down syndrome (American Academy of Pediatrics 1994). [D2]

2. It is recommended that the primary care physician be responsible for the child's general health care, and that the primary care physician refer the child to other health professionals as needed (such as a developmental/behavioral pediatrician, medical geneticist, cardiologist, endocrinologist, ophthalmologist, ENT specialist, or audiologist). [D2]

Experimental and alternative therapies

3. It is important that physicians discuss unproven theories and experimental therapies with families of children with Down syndrome to discourage misinformation and to help the family develop realistic expectations about treatment options (American Academy of Pediatrics 1994). [D2]

4. It is important to recognize that if parents do not receive information about alternative therapies directly from their health-care provider, they may obtain that information from the proponents of those therapies and/or other parents, and this information may be limited and possibly biased and/or incorrect. [D2]

5. It is important to have a systematic method to facilitate an informed decision-making process in which parents and health-care professionals

work together to make an informed decision based on the overall goals for the child and family before initiating any intervention. [D2]

6. When considering an intervention, it may be useful to provide parents with a list of questions to consider in the decision-making process (see Table 18, page 151). [D2]

Nutrition Interventions, Vitamin Therapy, and Hormone Therapy

Because growth, nutrition, and metabolism are of particular importance for infants and young children with Down syndrome, there are several intervention methods that focus on these issues. The methods discussed in this section include standard therapies (such as nutrition intervention and diet counseling by a registered dietitian) as well as several therapies that are considered more investigational or controversial (such as megadoses of vitamins, low-dose oral zinc supplementation, or growth hormone). Thyroid therapy is also discussed. Thyroid disorders are more common in children with Down syndrome than in typically developing children.

Recommendations (Nutrition Intervention, Vitamin Therapy, and Hormone Therapy)

Importance of nutrition intervention

1. When Down syndrome is diagnosed, it is important to initiate assessments to determine appropriate interventions to address the nutritional needs of the child. It is appropriate to begin this process at the time of diagnosis and to continue the process as the child develops. [D2]

2. When assessing the need for nutritional interventions, it is important to consider factors that may affect nutritional intake, such as:
   - Issues related to breastfeeding
   - Issues related to oral-motor function, behavioral, and sensory feeding problems [D2]

3. Nutrition intervention by a registered dietitian can assist parents in understanding how to help their child achieve adequate intake of calories and nutrients (protein, carbohydrate, fat, vitamins, and minerals) to promote growth and development. [D2]

4. Nutrition intervention and diet counseling may be helpful in prevention of obesity in children with Down syndrome. [D2]

5. Nutrition intervention is particularly important for children with Down syndrome who have increased energy requirements due to cardiac and respiratory conditions. [D2]

Early Intervention Policy ❖ Nutrition services are considered early intervention services.

Components of nutrition intervention

6. Particular areas of nutrition intervention that may be useful include:
   - Ensuring a balanced diet to meet the nutritional needs of the child
   - Establishing appropriate foods for children with behavioral feeding problems (in order to promote oral motor development and accepting a wider range of foods)
   - Designing appropriate diets for children with oral motor feeding problems or other associated health conditions that may affect feeding (such as celiac disease)
   - Providing dietary counseling for the prevention of obesity
   - Providing dietary management of constipation (often related to hypotonicity and dietary inadequate fluids and fiber)
   - Providing dietary intervention for nutritional deficiencies [D2]

Vitamin and mineral supplement therapy

7. It is important to understand that megadoses of vitamins have not been found to improve the growth, development, behavior or health of children with Down syndrome.

   [B] (Bidder 1989, Coleman 1985/Frager 1985)

8. Vitamin supplements for young children (other than ordinary children's vitamins) are not recommended unless prescribed by a physician to correct a diagnosed vitamin deficiency. It is important to remember that high doses of vitamins and minerals are associated with side effects and toxicity. [D2]

9. There is no clear indication for administering increased doses of vitamin B6 (pyridoxine) to children with Down syndrome.

   [B] (Coleman 1985/Frager 1985)

10. The guideline panel found no evidence to support long-term, low-dose oral zinc supplementation to improve depressed immune response or to decrease infections in children with Down syndrome. [D1]

Early Intervention Policy ❖ The Early Intervention Program does not pay for dietary supplements.

Growth hormone therapy

11. The administration of growth hormone to children with Down syndrome is not standard practice and remains investigational. Routine use of growth hormone is not recommended for children with Down syndrome. The benefits and risks associated with the use of growth hormone in young children with Down syndrome have not been thoroughly studied. [D1]

12. For a child with documented growth hormone deficiency, the risks, benefits and long-term effects of growth hormone treatment need to be considered. [D1]

Early Intervention Policy ❖ The Early Intervention Program does not pay for growth hormone, thyroid, or other medications.

Thyroid hormone therapy

13. It is recommended that consultation with a pediatric endocrinologist be considered for any abnormal thyroid findings. [D2]

14. It is important that children with Down syndrome who have low levels of thyroid hormone be given appropriate replacement therapy. [D1]

15. It is important to recognize that children with Down syndrome often have transiently elevated TSH that reverts to normal without intervention. However, for children with persistently elevated TSH, it is recommended that thyroid supplementation be given, even when T_4 is normal, as there is a possibility of decompensation at any time during the first 3 years of life.

    [C] (Cutler 1986, Sharav 1991)

Oral-Motor/Feeding Interventions

Infants and young children with Down syndrome often have a variety of oral motor and feeding problems. Interventions for these problems include behavioral interventions to improve tongue posture, teaching parents some methods and techniques to facilitate their child's feeding and transition to solid foods, and palatal plate therapy.

Recommendations (Oral-Motor/Feeding Interventions)

Oral-motor/feeding interventions

1. It is important that professionally guided oral-motor interventions be carried out by persons with knowledge and experience in the specific area of the intervention focus. [D2]
2. It is important to consider developmental levels (not chronologic age) in making decisions about the child's readiness to progress in feeding. [D2]
3. It is important to consider ease of implementation by parents when considering oral-motor/feeding intervention options. [D2]
4. When planning intervention strategies to facilitate feeding in young children with Down syndrome, it may be useful to consider:
   - Parent-child groups
   - Parent-parent training [D2]
5. It may be useful to consider using behavioral and/or oral-motor intervention to improve tongue posture and encourage appropriate development of jaw, lip, and tongue movements used in eating, drinking, and speaking.

   [C] (Purdy 1987)
6. It is important to consider the need for medical management of chronic sinus and other respiratory conditions that may affect jaw and tongue position. A chronic open mouth posture may take the jaw and tongue out of position for effective swallowing and speech production. [D2]
7. It may be useful to consider palatal plate therapy as an additional option to other oral-motor interventions.

   [B] (Carlstedt 1996)

Interventions for Hearing and Ear Problems

Hearing and ear problems are commonly seen in young children with Down syndrome. Children with Down syndrome are particularly prone to otitis media with effusion (OME), which can be associated with either temporary or more chronic hearing loss, as well as increased incidence of sensorineural hearing loss.

Interventions for hearing loss may include assistive devices such as hearing aids and FM systems. An FM system is a type of amplification device, the purpose of which is to reduce the negative effects of noise and distance on the perception of speech. The main components of an FM system are a wireless FM transmitter (microphone) worn by the talker several inches away from the mouth, and an FM receiver that receives the FM microphone signal. There are several types of FM systems, such as personal FM systems and sound field systems.

Recommendations (Interventions for Hearing and Ear Problems)

Interventions for hearing loss

1. It is important to use intervention strategies that facilitate the acquisition of listening behaviors. For example, useful strategies might include:
   - Providing opportunities for exposure to a variety of sounds
   - Drawing the child's attention to the sounds in the environment [D2]
2. If a hearing loss is present, it is recommended that hearing aids be considered. If the loss is conductive, hearing aids can be used on a temporary or an as needed basis. [D2]

Early Intervention Policy ❖ Personal amplification devices such as hearing aids are considered assistive technology devices under the Early Intervention Program.

3. For children who have difficulty discriminating speech in a background of noise because of hearing loss or an auditory processing disorder, it may be useful to consider an FM system, either to supplement hearing aids or as an alternative to hearing aids, as appropriate. [D2]
4. It may be helpful to consider behavior modification for young children who pull out their hearing aids. [D2]

Interventions for ear problems

5. It is recommended that if pressure equalization (PE) tubes are surgically placed in a child with Down syndrome, the child have a hearing test after tube placement and the child be monitored on an ongoing basis by a physician to make sure the tubes are functioning properly. [D2]

6. It is important to explain to parents that PE tubes for serous otitis media often fall out after several months and may need to be replaced. [D2]

Other Health-Related Interventions

This section on other "medical" interventions primarily includes two additional "controversial" treatments: piracetam and fetal-cell therapy.

Piracetam is a drug that is purported to have cognitive enhancing properties. It has been studied in clinical trials with adults with dementia, Parkinson's disease, and traumatic brain injury, and in children with learning disabilities. No consistent positive effects have been demonstrated in the clinical trials. No studies were found with young children with Down syndrome.

Fetal-cell therapy is the administration of freeze-dried cells derived from the fetal tissue of animals, specifically cows, sheep, or rabbits. Proponents of this therapy claim that it will improve the child's IQ, motor skills, social behavior, height, immunologic functioning, language skills, and memory, as well as ameliorating some of the physical features of Down syndrome. The guideline panel found no evidence that cell therapy is effective. Cell therapy is illegal in the United States.

Recommendations (Other Health-Related Interventions)

Medications and other health-related therapies

Early Intervention Policy ❖ The Early Intervention Program does not cover the costs of medical interventions, or surgical procedures, or primary health services (such as immunizations and well child care) that are needed by any child.

1. The guideline panel found no evidence to support the use of the oral medication piracetam as an intervention for young children with Down syndrome. [D1]

2. Fetal-cell therapy is not recommended for children with Down syndrome. [D1]

Table 19: Summary of Age-Specific Intervention Recommendations

BIRTH TO 4 MONTHS

Communication Interventions

- Assess the need for facilitation of oral-motor function and feeding
- Intervention by a qualified professional with the parent and the child as indicated by needs of the child and family
- Indications for a speech-language intervention during the birth-to-4-month period may include:
  - If the child has a hearing loss
  - If there is a feeding problem
  - If the parent indicates the need for more speech/language help/support
- Educate parents about techniques or activities that may stimulate communication development, including:
  - Tracking auditory stimulation
  - Orienting to voices
  - Vocalizing when spoken to

Cognitive Interventions

- Introduce teaching of cognitive skills as soon as possible using the principles of learning theory (Table 17, page 122)
- Initiate teaching of cognitive skills with the parent/caregiver, including:
  - Having the parent move an object for the infant to visually track
  - Saying the child's name
  - Telling the child the name or label for objects in view
  - Reading and singing to the child regularly

Motor Interventions

- Begin motor intervention within the first month. The focus of early motor intervention is:
  - To prevent compensatory movement patterns that may interfere with subsequent motor development
  - To prevent the development of deformities secondary to persistent atypical postures

Table 19: Summary of Age-Specific Intervention Recommendations

- To provide education and support to parents (e.g., to teach positioning and handling)
- Focus on development of postural control (ability to control head and trunk). Development of good postural control will help to facilitate future development of specific motor skills

AGE 4 TO 12 MONTHS

Communication Interventions

- Continue speech and language intervention with the parent/caregiver and child. Important components of therapy during this period include:
  - The encouragement of babbling
  - Use of informal gestures (such as pointing)
  - Direct intervention with child and caregiver with the emphasis on training of caregiver in language stimulation techniques appropriate for the individual child
- Provide language stimulation activities to promote development of expressive language
- Monitor oral-motor function (strength and coordination of lip, jaw, and tongue function), and assist as needed for feeding and speech

Cognitive Interventions

- Continue teaching of cognitive skills using the principles of learning theory
- Continue teaching of cognitive skills with the parent/caregiver, including:
  - Pulling a toy on a string out of reach, leaving the string within the infants reach
  - Partially hiding a toy within the child's reach
  - Hiding a small toy in an easy-to-open box
  - Showing the infant pictures with much color or contrast
  - Providing a mobile that moves when the infant moves in the crib

Motor Interventions

- Continue motor interventions related to postural control focusing on:
  - Development of postural control for head and upper trunk righting and upper extremity weight bearing in prone position (lying on stomach)
  - Development of sufficient trunk and head control for proper alignment in sitting
  - Development of postural control, scapular stability, and upper extremity strength to support fine motor control

Table 19: Summary of Age-Specific Intervention Recommendations

(Continued from previous page)

- Development of varied movements in the legs to support the development of standing
- Development of transitional movements (rolling, pivoting prone, belly crawling, getting in and out of sitting, etc.)
- Development of the ability to move against gravity to bring hands to midline and hands to mouth

- Begin motor interventions that focus on fine motor skills at approximately 6 months. Important components of fine motor interventions include:
  - Shoulder stability on stomach while reaching
  - Hand-to-mouth movements
  - Grip strength
  - Digital grasp
  - Transfer of objects hand to hand
  - Isolated use of index finger
- Resistive activities (strength training) may be beneficial to increase strength in young children with Down syndrome after the age of 4 months

AGE 12 TO 24 MONTHS

Communication Interventions

- Continue to receive speech/language therapy appropriate for the individual needs of the child, and continue parent training and education in language stimulation techniques
- Increase the frequency and intensity of the communication interventions from 12 to 24 months, as appropriate, because:
  - Speech language skills typically accelerate at this age, and there may be a need to facilitate this
  - The divergence between developmental progress of children with Down syndrome and typically developing children of the same age becomes greater
- Provide opportunities for linguistic interaction with other children to help stimulate and generalize language skills (playgroups, day care, therapeutic groups, etc.)
- Continuing oral-motor intervention to address muscle-based issues that affect the child's oral expressive output

(Continued from previous page)

Table 19: Summary of Age-Specific Intervention Recommendations

Cognitive Interventions

- Continue teaching of age-appropriate cognitive skills using the principles of learning theory
- Begin introduction to group learning experiences
- Continue teaching of cognitive skills with the parent/caregiver

Motor Interventions

- Continue intervention for development of fine motor skills. Important components of intervention include:
  - Prehension patterns
  - Grip strength
  - Finger and thumb control
  - Eye-hand coordination
  - In-hand manipulation
  - Bilateral coordination
  - Shoulder stability
  - Releasing objects
  - Refinement of grasp pattern
- Continuing intervention for the development of gross motor skills with a focus on the use of muscles control, posture, and movement rather than compensatory positions. Components to be addressed:
  - Development of creeping on hands and knees
  - Development of sufficient postural control to move in and out of sitting in varied patterns
  - Development of pull-to-stand, standing and cruising
  - Balance and coordination of trunk muscles
  - Use of coordinated control in hips knee, ankles, and feet
  - Use of varied movements for transition

AGE 24 TO 36 MONTHS

Communication Interventions

- Continued to receive speech/language therapy appropriate for the individual child and continue parent training and education in language stimulation techniques
- Provide in a structured peer group setting in order to:

(Continued from previous page)

Table 19: Summary of Age-Specific Intervention Recommendations

- Enhance language skills
- Facilitate communication sessions

- Provide opportunities for linguistic interaction with peers
- Speech language interventions for this age group should target:
  - Improving vocabulary (oral and signs)
  - Improving receptive and expressive language skills
  - Improving motor speech production

Cognitive Interventions

- Continue teaching of cognitive skills using the principles of learning theory
- Include opportunities for interaction with other children in structured and semistructured activities
- Reinforce cognitive skills through exposure to chronologic and/or developmental age peers
- Provide opportunities for generalization and exploration that enable the child to develop mastery and competencies within educational settings
- Continue teaching of cognitive skills with the parent/caregiver

Motor Interventions

- Continue interventions for development of fine motor skills. Important components of intervention include:
  - Use of writing materials
  - Turning knobs and lids
  - Rotating forearms
- Continue interventions for development of gross motor skills. Important components intervention include:
  - Development of independent walking
  - Appropriate equipment/toys to provide opportunities for independent upright movement
  - Development of stair climbing
  - Development of high level motor skills

(Continued from previous page)

APPENDIX A: METHODOLOGY TABLES

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Table A-1: General Criteria for Selecting Studies for In-Depth Review

To be selected for in-depth review by the panel, a scientific article had to meet all of the general criteria for in-depth review given below, as well as all the additional criteria for either studies about the developmental characteristics of young children with Down syndrome (Table A-2) or studies of intervention methods (Table A-4).

To meet the **general criteria** for in-depth review, studies had to:

- Be published in English in a peer-reviewed scientific/academic publication
- Provide original data about the topic of interest (or be a systematic synthesis of such data from other studies)
- Evaluate subjects of appropriate age (see Tables A-3 and A-4)

Table A-2: Criteria for Adequate Evidence: Developmental Characteristics

To be considered as adequate evidence about the **developmental characteristics** of young children with Down syndrome, studies had to meet the following criteria:

1. The study compares characteristics of children with Down syndrome with either:
   a. A comparison group of typically developing children, *or*
   b. A comparison group of children with general developmental delays (not acceptable if the comparison group has a delay related to a specific condition such as autism, Williams syndrome, etc.)
2. The study evaluates children of the appropriate age (meets at least one of the following criteria):
   a. The majority of subjects are ≤48 months of age, *or*
   b. The study group is described as "infant," "toddler," or "early intervention" (EI).
3. The study includes data on the child (not just parent reaction or behavior)
4. The data are presented separately for each group of interest (using similar assessment methods for each group)
5. The study presents original quantitative data for characteristics/outcomes of interest and appropriate statistical analysis of results

There is a notable difference in the type of scientific evidence obtained from studies about developmental characteristics compared with studies evaluating the efficacy of an intervention or assessment method. Because studies of developmental characteristics provide only descriptive evidence, all studies of developmental characteristics are rated as *Intermediate Quality/Applicability*.

Recommendations based on information from studies about the developmental characteristics of young children with Down syndrome are indicated with a subscript [$_{dc}$] following the Evidence Rating.

Table A-3: Criteria for Adequate Evidence: Health Assessment Studies

To be considered as adequate evidence about the **health assessment** (thyroid function and growth hormone) for young children with Down syndrome, studies had to meet the following criteria:

A. Meet all the general criteria for evidence in Table A-1, and

B. Meet the following additional criteria for studies of assessment methods:
   - Evaluate a health assessment method currently available to providers in the U.S.
   - Provide an adequate description of the assessment method evaluated
   - Include at least 10 subjects with the condition and at least 10 without the condition
   - Present original quantitative data for outcomes of interest and appropriate statistical analysis of results

Studies were considered to have *high quality/applicability* if:

- All subjects are ≤48 months of age *or* the mean age of the subjects is ≤36 months or all subjects described as "infant," "toddler," *or* "early intervention" (EI)
- Study design, study population, and results adequately described and no significant issues noted regarding factors which might bias results

Studies were considered to have *intermediate quality/applicability* if:

- Age range of subjects is >48 months of age or the mean age of the subjects is >36 months or not reported
- Study design, study population, and results not adequately described or issues noted regarding factors which might bias results

Table A-4: Criteria for Intervention Studies

Articles meeting the following quality and applicability criteria were considered adequate evidence about efficacy of **intervention methods** for young children with Down syndrome.

For *all studies* of intervention methods, studies had to:

A. Meet all the general criteria for evidence in Table A-1, and

B. Meet the following additional criteria for studies of intervention methods:

- The study evaluates an intervention method currently available to providers in the U.S. (and not an obsolete or experimental method)
- The article provides an adequate description of the intervention method evaluated, or provides a reference where a description can be found
- The study addresses efficacy of the intervention using functional outcomes important for the child's overall development, and has child-centered outcomes, not just parent-related outcomes
- Identical outcome assessment methods and protocols are used for all subjects
- The article provides adequate quantitative description of study findings and appropriate statistical analysis of results

For single-subject design studies (*considered intermediate quality/applicability*)

Single-subject design studies were considered acceptable if:

- Study has at least 3 subjects with Down syndrome ≤48 months of age, or the mean age of the subjects is ≤48 months
- Study uses an acceptable single-subject design methodology (either multiple baseline or ABAB design)

Group Studies

Study has an intervention group and a comparison group (receiving an alternate intervention or no intervention)

Studies were considered to have high quality/applicability if:

- All subjects have Down syndrome
- All subjects are <48 months of age or the mean age of the subjects is <36 months or all subjects described as infant, toddler, or early intervention (EI)
- Study design, study population, and results adequately described, and no significant issues noted regarding factors that might bias results
- Outcomes are reported for at least 10 subjects in each group
- Assignment of subjects to intervention or comparison groups is done randomly or using some other method not likely to bias study results

Studies were considered to have *intermediate quality/applicability* if:

- All subjects have some type of developmental disability and at least 50% have Down

Table A-4: Criteria for Intervention Studies

syndrome

- Age range of subjects is >48 months of age or the mean age of the subjects is >36 months or not reported
- Study design, study population, and results not adequately described or issues noted regarding factors which might bias results
- Method of assigning subjects to intervention and comparison groups is not specified, or the study is a retrospective comparison of existing groups
- The diagnoses and important baseline characteristics of subjects are reported and are comparable between groups
- Outcomes are reported for at least 8 subjects per group

(Continued from previous page)

Table A-5: Strength of Evidence Ratings for Guideline Recommendations

Each recommendation in Chapters III and IV is followed by one of the four "strength of evidence" ratings described below. These "strength of evidence" ratings indicate the amount, general quality, and clinical applicability (to the guideline topic) of scientific evidence used as the basis for each guideline recommendation.

Recommendations based on information from studies about the developmental characteristics are given Evidence Ratings noted with a subscript [$_{dc}$] following the Evidence Rating.

[A] = **Strong evidence** is defined as evidence from two or more studies that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, with the evidence consistently and strongly supporting the recommendation.

[B] = **Moderate evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, and where the evidence supports the recommendation.

[C] = **Limited evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had moderate quality or applicability to the topic, and where the evidence supports the recommendation.

[D] = **Panel consensus opinion** (either [D1] or [D2]):

- [D1] = **Panel consensus opinion** based on information not meeting criteria for adequate evidence about efficacy on topics where a systematic review of the literature was done.
- [D2] = **Panel consensus opinion** on topics where a systematic literature review was not done.

APPENDIX B: SUMMARY OF EVIDENCE

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DEVELOPMENTAL CHARACTERISTICS RESEARCH

A. Evidence on Cognitive Development

The process of cognitive development in a very young child is complex and does not occur in isolation. The cognitive domain overlaps with all other developmental domains (such as communication, motor, social, and self-help skills, etc.). The studies reviewed in this section were considered by the panel to be primarily evaluating cognitive development, although other developmental domains were also assessed in these studies. In a similar manner, many of the studies evaluated for other developmental domains also evaluate cognitive processes to some degree.

There were 13 articles about the cognitive development of young children with Down syndrome that met the panel's criteria for adequate evidence about this topic. The studies are grouped in the following subtopics:

- General cognitive development
- Attention and exploration
- Learning and memory
- Reasoning and problem solving

Studies Meeting Criteria for Evidence

1. **Berry,** P. and Gunn, P. Maternal influence on the task behaviour of young Down's syndrome children. *Journal of Mental Deficiency Research* 1984; 28[4]: 269-274.

2. **Berry,** P., Gunn, P., and Andrews, R. J. The behaviour of Down's syndrome children using the 'Lock Box': A research note. *Journal of Child Psychology and Psychiatry* 1984A; 25[1]: 125-131.

3. **Bradley-Johnson,** S., Friedrich, D. D., and Wyrembelski, A. R. Exploratory behavior in Down's syndrome and normal infants. *Applied Research in Mental Retardation* 1981; 2[3]: 213-228.

4. **Carr,** J. Mental and motor development in young mongol children. *Journal of Mental Deficiency Research* 1970; 14: 205-220.

5. **Dunst,** C. J. Stage transitioning in the sensorimotor development of Down's syndrome infants. *Journal of Mental Deficiency Research* 1988; 32[5]: 405-410.

6. **Krakow,** J. B. and Kopp, C. B. The effects of developmental delay on sustained attention in young children. *Child Development* 1983; 54[5]: 1143-1155.

7. **Lewis,** V. A. and Bryant, P. E. Touch and vision in normal and Down's syndrome babies. *Perceptio*n 1982; 11[6]: 691-701.

8. **MacTurk,** R. H., Vietze, P. M., McCarthy, M. E., McQuiston, S., and Yarrow, L. J. The organization of exploratory behavior in Down syndrome and nondelayed infants. *Child Development* 1985; 56[3]: 573-581.

9. **Loveland**, K. A. Behavior of young children with Down syndrome before the mirror: Exploration. *Child Development* 1987; 58[3]: 768-778.

10. **Loveland,** K. A. Behavior of young children with Down syndrome before the mirror: Finding things reflected. *Child Development* 1987A; 58[4]: 928-936.

11. **Ohr,** P. S. and Fagen, J. W. Conditioning and long-term memory in three-month-old infants with Down syndrome. *American Journal of Mental Retardation* 1991; 96[2]: 151-162.

12. **Ohr,** P. S. and Fagen, J. W. Temperament, conditioning, and memory in 3-month-old infants with Down syndrome. *Journal of Applied Developmental Psychology* 1993; 14[2]: 175-190.

13. **Wishart,** J. G. Performance of young nonretarded children and children with Down syndrome on Piagetian infant search tasks. *American Journal of Mental Deficiency* 1987; 92[2]: 169-177.

Panel Conclusions (Cognitive Development)

General development

1. Children with Down syndrome, ranging from 1 month to 2 years of age, compared with typically developing children matched for gender, age, and social class, when evaluated for general cognitive and motor development:
    - Have moderately lower mental and motor development scores at 6 weeks and 6 months of age
    - Show a drop in scores at 10 months and 15 months and a flattening out of scores by 2 years of age
    - Exhibit greater fluctuations in mental developmental scores (Carr 1970)

Attention and exploration

2. Compared with typically developing children matched for chronologic age, 1-year-old children with Down syndrome who are presented with novel objects tend to:
   - Spend a similar amount of time in visual exploration
   - Spend less time mouthing and manipulating objects
   - Spend less time manipulating each new object when multiple objects were introduced sequentially (Bradley-Johnson 1981)
3. Compared with typically developing children matched for mental age, 1- to 3-year-old children with Down syndrome who are presented with new objects tend to spend less time looking at and touching the new objects (Lewis 1982).
4. Children with Down syndrome from 1 to 3 years old and typically developing children matched for mental age who are presented with new objects react similarly in the following ways:
   - Children gaze at objects longer when the object was touchable
   - Children gaze at and touched 3-dimensional objects less than flat objects
   - Older children both gaze at and touch objects more than younger children do (Lewis 1982)
5. Compared with typically developing children matched for either developmental or mental age, 2- to-3-year-old children with Down syndrome, when playing with toys, tend to:
   - Have similar levels of sustained attention during play
   - Have similar amounts of developmentally appropriate play
   - Display more throwing behaviors
   - Glance up less during play
   - Look less at people when not engaged with toys
   - Spend more time unoccupied when not engaged with toys (Krakow 1983)
6. Compared with typically developing children matched for mental age, children with Down syndrome over 18 months old, when given a task to find an object:
   - Use a greater number and variety of exploratory behaviors

- Attempt fewer active but incorrect strategies to complete the task
- Need similar amounts of prompting
- Take similar amounts of time to complete the task (Loveland 1987/Loveland 1987A)

7. Mental age is the best predictor of whether a child will successfully complete a learning task for both children with Down syndrome over 18 months old and typically developing children (Loveland 1987/Loveland 1987A).

8. Compared with typically developing children matched for mental age, children with Down syndrome over 18 months old, when placed in front of a mirror, tend to:
   - Spend a greater amount of time looking in the mirror
   - Be more attentive to and less likely to lose interest in the mirror (Loveland 1987/Loveland 1987A)

9. Compared with typically developing children matched for mental age, 9-month-old children with Down syndrome, when presented with new objects tend to:
   - Spend equal time attending to the new objects
   - Spend more time looking at the new object
   - Spend less time exploring the new objects (MacTurk 1985)

Learning and memory

10. Compared with typically developing children matched for chronologic age, 4-month-old children with Down syndrome tend to:
    - Have a similar ability to learn operant conditioning tasks
    - Display a similar temperament when learning new tasks
    - Be less likely to be positively reinforced by visual and auditory stimulation (Ohr 1991, Ohr 1993)

Reasoning and problem solving

11. Compared with typically developing children matched for mental age, 3- to 4-year-old children with Down syndrome, when performing a problem-solving task of removing toys from a lock box, show less success in the task. As with typically developing children, competence and organization tends to increase with increases in mental age (Berry 1984).

12. Compared with typically developing children matched for chronologic age, 3- to 4-year-old children with Down syndrome, when performing a problem-solving task (removing from a lock box), tend to:
    - Exhibit more unsuccessful attempts
    - Exhibit fewer aimless actions when mother is present
    - Exhibit less exploration with fewer problem-solving strategies
    - Be less likely to repeat strategies (patterns of actions that were previously successful) (Berry 1984A)
13. Compared with typically developing children matched for chronologic age, when measuring the progress in sensorimotor development, children with Down syndrome tend to:
    - Take less time to move to the next stages for gestural imitation and spatial relation
    - Take more time to move to the next stages in all other domains (Dunst 1988)
14. Compared with typically developing children matched for chronologic age, 3- to 4-year-old children with Down syndrome, when given a problem-solving task using progressively difficult repeated trials, tend to:
    - Improve with each session
    - Be lower with the first session but equal in the following sessions
    - Exhibit false fails (purposely responding incorrectly) less frequently (Wishart 1987)

B. Evidence on Communication/Language Development

This section reviews the evidence about communication/language development in young children with Down syndrome. There were nine studies that met the panel's criteria for adequate evidence about this topic. The studies are grouped in the following subtopics:

- Early vocalization
- Gestures and nonverbal communication
- Verbal language development
- Auditory preferences

Studies Meeting Criteria for Evidence

1. **Cobo-Lewis,** A. B., Oller, D. K., Lynch, M. P., and Levine, S. L. Relations of motor and vocal milestones in typically developing infants and infants with Down syndrome. *American Journal of Mental Retardation* 1996; 100[5]: 456-467.

2. **Caselli,** M. C., Vicari, S., Longobardi, E., Lami, L., Pizzoli, C., and Stella, G. Gestures and words in early development of children with Down syndrome. *Journal of Speech, Language and Hearing Research* 1998; 41[5]: 1125-1135.

3. **Franco,** F. and Wishart, J. G. Use of pointing and other gestures by young children with Down syndrome. *American Journal of Mental Retardation* 1995; 100[2]: 160-182.

4. **Glenn,** S. M., Cunningham, C. C., and Joyce, P. F. A study of auditory preferences in nonhandicapped infants and infants with Down's syndrome. *Child Development* 1981; 52[4]: 1303-1307.

5. **Harris,** J. What does mean length of utterance mean? Evidence from a comparative study of normal and Down's syndrome children. *British Journal of Disorders of Communication* 1983; 18[3]: 153-169.

6. **Lynch,** M. P., Oller, D. K., Steffens, M. L., Levine, S. L., Basinger, D. L., and Umbel, V. Onset of speech-like vocalizations in infants with Down syndrome. *American Journal of Mental Retardation* 1995; 100[1]: 68-86.

7. **Mahoney,** G., Glover, A., and Finger, I. Relationship between language and sensorimotor development of Down syndrome and nonretarded children. *American Journal of Mental Deficiency* 1981; 86[1]: 21-27.

8. **Mundy,** P., Sigman, M., Kasari, C., and Yirmiya, N. Nonverbal communication skills in Down syndrome children. *Child Development* 1988; 59[1]: 235-249.

9. **Steffens,** M. L., Oller, D. K., Lynch, M., and Urbano, R. C. Vocal development in infants with Down syndrome and infants who are developing normally. *American Journal of Mental Retardation* 1992; 97[2]: 235-246.

Panel Conclusions (Communication/Language Development)

Early vocalization

1. Children with Down syndrome develop canonical babbling later than typically developing children, although the ranges of onset overlap (Cobo-Lewis 1996, Lynch 1995). Ages of onset of canonical babbling (observed at home) were:
   - 6.6 to 13.3 months for children with Down syndrome (mean = 9 months)
   - 4.3 to 8.4 months in typically developing children (mean = 6 months) (Lynch 1995)
2. There is a great deal of variability in a child's use of early vocalizations both for children with Down syndrome and typically developing children. Children with Down syndrome tend to use canonical babbling less consistently than do typically developing children. There are also differences between time of onset of canonical babbling in the home and in the laboratory. Therefore, a one-time assessment may be misleading (Lynch 1995, Steffens 1992).
3. In children with Down syndrome, an earlier onset of canonical babbling is correlated with more advanced social and communication development at 27 months (Lynch 1995).

Gestures and nonverbal communication

4. Children with Down syndrome and typically developing children both tend to increase their use of gestures as the level of receptive language (word comprehension) increases (Caselli 1998).
5. Compared with typically developing children at similar levels of language development, children with Down syndrome use more gestures (Caselli 1998, Franco 1995).
6. Children with Down syndrome show deficits in nonverbal communication skills (gestures) that are considered necessary precursors for developing verbal communication (Mundy 1988).
7. Compared with typically developing children at similar levels of language or cognitive development, children with Down syndrome use gestures differently. Specifically, children with Down syndrome:
   - Use more nonverbal social interactions

- Use more social referencing when pointing
- Use a similar frequency of reaching for objects
- Use less nonverbal requesting behaviors (Franco 1995, Mundy 1988)

8. Children with Down syndrome tend to use gestures differently than do other children with cognitive delays. Children with Down syndrome:
   - Use more nonverbal social interactions
   - Use less nonverbal requesting behaviors (Mundy 1988)

Verbal language development

9. Compared with typically developing children, children with Down syndrome show delays in both receptive and expressive language development. The degree of delay becomes greater as children get older (Caselli 1998, Harris 1983, Mahoney 1981, Mundy 1988).

10. Even when compared with typically developing children matched for mental age, children with Down syndrome show delays in expressive language development. Children with Down syndrome show a greater delay in expressive language than in receptive language (Mahoney 1981, Mundy 1988).

11. At an early stage of verbal language development (single-word utterances), children with Down syndrome have an expressive vocabulary similar in size to that of typically developing children matched for level of word comprehension (Caselli 1998).

12. For children with Down syndrome:
    - Higher levels of receptive and expressive language are associated with development of object permanence
    - Higher levels of receptive language are associated with gestural imitation (Mahoney 1981)

13. As children advance from single-word to multiword utterances, children with Down syndrome use different types of words and have different patterns of language compared with typically developing children matched for mean length of utterance. Specifically, children with Down syndrome:
    - Use fewer single-word utterances that make use of operators
    - Use fewer multiword utterances that make use of operators
    - Use fewer words indicating nonexistence or disappearance (such as gone, no more)
    - Use more rote utterances (Harris 1983)

14. Mean length of utterance may not be an accurate predictor of other language abilities (Harris 1983).

15. Children with Down syndrome who have better verbal expressive language tend to have better nonverbal communication skills (Mundy 1988).

Auditory preferences

16. The majority of infants with Down syndrome, as well as the majority of typically developing children matched for mental age, prefers to listen to a human voice rather than to musical instruments (Glenn 1981).

Communication and language milestones

17. Developmental milestones for communication and language have been established for typically developing children. These milestones specify the age at which most typically developing children will have displayed a particular communication skill or behavior (NYSDOH Communication Disorders Guidelines 1999).

18. Compared with typically developing children, the average age when children with Down syndrome reach each specific communication milestone is later, and the range of ages for attaining each milestone is broader (Cunningham 1996).

19. The broader age range of communication milestone attainment may be at least partly because children with Down syndrome vary greatly in their degree of cognitive delay (Carr 1970, Cunningham 1996).

C. Evidence on Social Development

There were 15 studies about the social development of young children with Down syndrome that met the panel's criteria for adequate evidence about this topic. The studies were grouped in the following two general subtopics:

- Social attention
- Social interaction

Studies Meeting Criteria for Evidence

1. **Bressanutti,** L., Sachs, J., and Mahoney, G. Predictors of young children's compliance to maternal behavior requests. *International Journal of Cognitive Education and Mediated Learning* 1992; 2[3]: 198-209.

2. **Carvajal,** F. and Iglesias, J. Mother and infant smiling exchanges during face-to-face interaction in infants with and without Down syndrome. *Developmental Psychobiology* 1997; 31[4]: 277-286.

3. **Cielinski,** K. L., Vaughn, B. E., Seifer, R., and Contreras, J. Relations among sustained engagement during play, quality of play, and mother/child interaction in samples of children with Down syndrome and normally developing toddlers. *Infant Behavior and Development* 1995; 18 [2]: 163-176.

4. **Crown,** C. L., Feldstein, S., Jasnow, M. D., Beebe, B., and Jaffe, J. Down's syndrome and infant gaze: Gaze behavior of Down's syndrome and nondelayed infants in interactions with their mothers. *Acta Paedopsychiatrica*. 1992; 55[1]: 51-55.

5. **Gunn,** P., Berry, P., and Andrews, R. J. Looking behavior of Down syndrome infants. *American Journal of Mental Deficiency* 1982; 87[3]: 344-347.

6. **Kasari,** C., Mundy, P., Yirmiya, N., and Sigman, M. Affect and attention in children with Down syndrome. *American Journal of Mental Retardation* 1990; 95[1]: 55-67.

7. **Kasari,** C., Freeman, S., Mundy, P., and Sigman, M. D. Attention regulation by children with Down syndrome: Coordinated joint attention and social referencing looks. *American Journal of Mental Retardation* 1995; 100[2]: 128-136.

8. **Knieps**, L. J., Walden, T. A., and Baxter, A. Affective expressions of toddlers with and without Down syndrome in a social referencing context. *American Journal of Mental Retardation* 1994; 99[3]: 301-312.

9. **Landry,** S. H. and Chapieski, M. L. Joint attention and infant toy exploration: Effects of Down syndrome and prematurity. *Child Development* 1989; 60[1]: 103-118.

10. **Landry,** S. H. and Chapieski, M. L. Joint attention of six-month-old Down syndrome and preterm infants: I. Attention to toys and mother. *American Journal of Mental Retardation* 1990; 94[5]: 488-498.

11. **Landry,** S. H., Garner, P. W., Pirie, D., and Swank, P. R. Effects of social context and mothers' requesting strategies on Down's syndrome children's social responsiveness. *Developmental Psychology* 1994; 30[2]: 293-302.

12. **Mahoney,** G., Fors, S., and Wood, S. Maternal directive behavior revisited. *American Journal of Mental Retardation* 1990; 94[4]: 398-406.

13. **Ruskin,** E. M., Kasari, C., Mundy, P., and Sigman, M. Attention to people and toys during social and object mastery in children with Down syndrome. *American Journal of Mental Retardation* 1994; 99[1]: 103-111.

14. **Tannock,** R. Mothers' directiveness in their interactions with their children with and without Down syndrome. *American Journal of Mental Retardation* 1988; 93[2]: 154-165.

Panel Conclusions (Social Development)

Social attention

1. Compared with typically developing children matched for chronological age, infants with Down syndrome from 4 to 9 months of age spend more time gazing at their mothers when engaged in play with their mothers (Crown 1992, Gunn 1982).
2. Compared with typically developing children matched for mental age, children with Down syndrome from 16 to 28 months of age, when engaged in play with an unfamiliar adult, tend to:
   - Show similar levels of joint attention
   - Spend more time looking at the adult's face and spend more time looking away from the interaction
   - Spend less time looking at objects that are not the main focus of play
   - Use less social referencing
   - Have more shifts in affect (facial expression) (Kasari 1990, Kasari 1995)
3. The extent to which children with Down syndrome (from age 16 to 28 months) engage in play with an unfamiliar adult generally correlates with:
   - Expressive language skills at 16 months of age
   - Nonverbal joint attention skills at 28 months of age (Kasari 1990)
4. Compared with other children with developmental delays matched for mental and motor age, 12-month-old children with Down syndrome, in responding to their mothers' attempts to direct the child's attention during play:
   - Are equally likely to respond with a look or with no response
   - Are less likely to respond by manipulating a toy introduced by the mother (Landry 1989)

5. When engaged in play with toys, 7- to 8-month old children with Down syndrome tend to:
   - Spend more time looking at their mothers and less time looking at toys
   - Show more positive affect (facial expressions) during independent play than during joint play (Landry 1990)
6. Compared with high risk infants matched for mental and motor age, 7- to 8-month-old children with Down syndrome engaged in play with toys:
   - Spend more time looking at their mothers and show a more positive affect when engaged in independent play than during joint play
   - Are less responsive to their mothers' attempts to redirect attention during joint play (Landry 1990)
7. When presented with two social interaction situations with an adult, children with Down syndrome, compared with typically developing children matched for language level:
   - Are more likely to attend to and participate in a verbal social interaction (singing a song with an adult)
   - Are less likely to play independently with toys presented by the adult
   - Are less likely to smile when given toys, but equally likely to smile during verbal social interaction (Ruskin 1994)

Social interaction

8. When presented with unfamiliar and ambiguous situations in the presence of their mothers, children with Down syndrome age 1 1/2 to 3 1/2 years, compared with typically developing children matched for mental age:
   - Look at their mothers less often and for a shorter period of time
   - Are less likely to match their mothers' fearful expressions
   - Show similar intensity and lability of facial expressions (Knieps 1994)
9. Children with Down syndrome who are 2 to 4 years old and typically developing children matched for developmental or mental age respond similarly to their mothers' requests when engaged in play. Children in both groups:
   - Are more likely to respond to requests when there is a higher contingency

- Have more appropriate and higher quality responses (i.e., the child is more likely to attempt or complete a task) when requests are less difficult and have higher contingency (consequence) (Bressanutti 1992)

10. Children with Down syndrome tend to have a similar quality of play as that of typically developing children matched for developmental or mental age, when playing both with their mothers and playing independently (Cielinski 1995).

11. When engaged in play with their mothers, children with Down syndrome, compared with typically developing children matched for developmental or mental age, tend to:
    - Spend less time in play
    - Have shorter bouts of play, but more bouts of play per minute (Cielinski 1995)

12. Compared with typically developing 3- to 14-month-old infants matched for chronologic age, infants with Down syndrome tend to:
    - Spend less time smiling at their mother when engaged with their mother in normal play
    - Spend a similar amount of time smiling at their mother when the mother both was and was not interacting in play activities (Carvajal 1997)

13. For children with Down syndrome, the amount of time a child spends engaged with toys tends to increase when the mother is more directive (Cielinski 1995).

14. Compared with mothers of typically developing children matched for developmental age, the mothers of children with Down syndrome tend to be more directive in social interactions with their child, especially when the interaction setting is less structured and more open-ended (Cielinski 1995, Landry 1994, Mahoney 1990, Tannock 1988).

15. When engaged in play with their mothers (either carrying out difficult tasks or engaged in pretend play), children with Down syndrome, compared with typically developing children matched for developmental age, tend to:
    - Be less likely to comply to requests initiated by their mothers
    - Be more likely to comply to a directive request than to a suggestive request from their mothers

- Have fewer social interactions in both types of play situations (Landry 1994)

16. When engaged in play with their mothers, 1- to 5-year-old children with Down syndrome, compared with typically developing children matched for developmental age, tend to have a similar frequency of utterances or turns taken (Tannock 1988).

Social milestones

17. Compared with typically developing children, the average age when children with Down syndrome reach each specific social development milestone is later, and the range of ages for attaining each milestone is broader (Cunningham 1996).

18. The broader age range of social development milestone attainment may be at least partly because children with Down syndrome vary greatly in their degree of cognitive delay (Carr 1970, Cunningham 1996).

Patterns of maternal interactions with child

19. Compared with mothers of other children with developmental delays matched for mental and motor age, mothers of children with Down syndrome when engaged in play with their child:
    - Are more likely to introduce a toy when the child is not involved with anything
    - Are more likely to physically reorient the child (Landry 1989)

20. Mothers of children with Down syndrome who are engaged in play with their children tend to use more requests for action and fewer requests for attention when interacting with their child. The opposite pattern was found for mothers of typically developing children matched for developmental age (Mahoney 1990).

21. Compared with mothers of typically developing children matched for developmental age, the mothers of children with Down syndrome tend to show greater control in turn-taking and in choosing the topic of the interaction when interacting with their children (Tannock 1988).

D. Evidence on Motor Development

This section reviews the evidence about motor development in young children with Down syndrome. There were six studies that met the panel's criteria for adequate evidence about this topic. Five of the six studies on motor development

were grouped as postural reaction studies. The sixth study (Cobo-Lewis 1996) evaluated the relationship between motor development and vocal milestones and is also reviewed as a communication/language development study.

Studies Meeting Criteria for Evidence

1. **Cobo-Lewis,** A. B., Oller, D. K., Lynch, M. P., and Levine, S. L. Relations of motor and vocal milestones in typically developing infants and infants with Down syndrome. *American Journal of Mental Retardation* 1996; 100[5]: 456-467.

2. **Haley,** S. M. Postural reactions in infants with Down syndrome: Relationship to motor milestone development and age. *Physical Therapy* 1986; 66[1]: 17-22.

3. **Haley,** S. M. Sequence of development of postural reactions by infants with Down syndrome. *Developmental Medicine and Child Neurology* 1987; 29[5]: 674-679.

4. **Rast,** M. M. and Harris, S. R. Motor control in infants with Down syndrome. *Developmental Medicine and Child Neurology* 1985; 27[5]: 682-685.

5. **Ulrich,** B. D. and Ulrich, D. A. Spontaneous leg movements of infants with Down syndrome and nondisabled infants. *Child Development* 1995; 66[6]: 1844-1855.

6. **Ulrich,** B. D., Ulrich, D. A., Angulo-Kinzler, R., and Chapman, D. D. Sensitivity of infants with and without Down syndrome to intrinsic dynamics. *Research Quarterly for Exercise and Sport* 1997; 68[1]: 10-19.

Panel Conclusions (Motor Development)

Postural reactions

1. Motor delays or motor deficits can be observed in infants with Down syndrome as early as 3 to 5 months of age (Rast 1985).

2. Focusing on only motor milestones while neglecting postural reactions (such as head righting) may give a false impression that motor development is progressing normally in young infants with Down syndrome (Rast 1985).

3. Infants with Down syndrome have difficulty adjusting their heads in space against gravity and have less antigravity control of lower extremities (Rast 1985).

4. Children with Down syndrome may exhibit atypical movement patterns that may interfere with future motor development. Some of these atypical patterns may reflect the child's efforts to compensate for low muscle tone (hypotonia), which is common in children with Down syndrome (Rast 1985).
5. The times of onset for postural reactions are closely associated with the level of motor development in both children with Down syndrome and typically developing children, but the association is greater with children with Down syndrome (Haley 1986).
6. By 4 months of age, differences in postural reactions can be seen between children with Down syndrome and typically developing children. After 5 months of age, the rate of development of postural reactions is slower in infants with Down syndrome than in typically developing infants matched for chronologic age (Haley 1986).
7. The level of motor development is more closely associated with chronologic age for typically developing infants, compared with infants with Down syndrome (Haley 1986).
8. There is no significant difference in rank in which righting and equilibrium factors (indicators of postural control) appear in children with Down syndrome and typically developing children (Haley 1987).
9. Well-developed postural reactions (protective reactions, righting reactions, and equilibrium reactions), which allow an individual to maintain body alignment when stationary and during movement, are a necessary precursor to later motor development including crawling, standing, and walking, as well as adaptive skills. Children with Down syndrome are delayed in developing all postural reactions compared with typically developing children of the same chronologic age (Haley 1986, Haley 1987, Rast 1985).
10. Children with Down syndrome developed protective reactions relatively sooner in the sequence of motor development, and righting and equilibrium reactions are developed later, compared with typically developing children. This delay in development of righting and equilibrium reactions may lead the child with Down syndrome to develop atypical compensatory movement patterns (for head righting, standing, etc.) (Haley 1986, Haley 1987, Rast 1985).

Spontaneous movements

11. The frequency and duration of spontaneous movements does not differ between 5-month-old infants with Down syndrome and typically developing infants matched for either chronologic or motor age (Ulrich 1995).
12. Children with Down syndrome at 5 months of age have less complex spontaneous leg movements compared with typically developing infants matched for either chronologic or motor age (Ulrich 1995).
13. Five-month-old infants with Down syndrome who display more complex spontaneous kicking movements tend to walk at an earlier age compared with Down syndrome children who do not show these kicking movements. This suggests that repeated complex spontaneous movements may be important for facilitating the later development of stable motor behavior patterns in infants with Down syndrome (Ulrich 1995).
14. Infants with Down syndrome who have a greater range of motion at the hip and the knees at 5 months of age tend to have a later onset of walking than do other children with Down syndrome. This may be because increased joint flexibility combined with general hypotonicity may make these children less stable when standing and walking (Ulrich 1995).
15. Both the type of environmental stimulation and order of stimulation affect movement frequency. There is more movement with verbal than with visual stimuli (Ulrich 1995).
16. When confronted with different physical situations affecting motor movements, infants with Down syndrome require a higher threshold of sensory input in order to adapt to situations and display less intense changes in motor output when compared with typically developing infants matched for chronologic or motor age (Ulrich 1997).
17. It is possible that children with Down syndrome have a reduced sensitivity to their own “internal dynamics,” which could explain why they develop functional motor and adaptive skills later than typically developing children (Ulrich 1997).

Motor milestones

18. Compared with typically developing children, the average age when children with Down syndrome reach each specific motor milestone is later,

and the range of ages for attaining each milestone is broader (Cobo-Lewis 1996, Cunningham 1996).

E. Evidence on Temperament/Behavior Styles

This section reviews the evidence about the temperament/behavior styles of young children with Down syndrome. There were seven studies that met the panel's criteria for adequate evidence about the subject.

Studies Meeting Criteria for Evidence

1. **Bridges,** F. A. and Cicchetti, D. Mothers' ratings of the temperament characteristics of Down syndrome infants. *Developmental Psychology* 1982; 18[2]: 238-244.
2. **Gunn,** P. and Berry, P. The temperament of Down's syndrome toddlers and their siblings. *Journal of Child Psychology and Psychiatry* 1985; 26[6]: 973-979.
3. **Huntington,** G. S. and Simeonsson, R. J. Down's syndrome and toddler temperament. Child: Care, *Health and Development* 1987; 13[1]: 1-11.
4. **Marcovitch**, S., Goldberg, S., MacGregor, D. L., and Lojkasek, M. Patterns of temperament variation in three groups of developmentally delayed preschool children: Mother and father ratings. *Journal of Developmental and Behavioral Pediatrics* 1986; 7[4]: 247-252.
5. **Marcovitch,** S., Goldberg, S., Lojkasek, M., and MacGregor, D. L. The concept of difficult temperament in the developmentally disabled preschool child. *Journal of Applied Developmental Psychology* 1987; 8[2]: 151-164.
6. **Rothbart,** M. K. and Hanson, M. J. A caregiver report: Comparison of temperamental characteristics of Down syndrome and normal infants. *Developmental Psychology* 1983; 19[5]: 766-769.
7. **Vaughn,** B. E., Contreras, J., and Seifer, R. Short-term longitudinal study of maternal ratings of temperament in samples of children with Down syndrome and children who are developing normally. *American Journal of Mental Retardation* 1994; 98[5]: 607-618.

Panel Conclusions (Temperament/Behavior Styles)

1. In general, a young child's temperament appears fairly stable as the child grows older, both for children with Down syndrome and for typically developing children (Huntington 1987).

2. Children with Down syndrome show less persistence in activities than do typically developing children when matched either on chronologic or mental age (Bridges 1982, Gunn 1985, Huntington 1987, Marcovitch 1986).
3. Compared with typically developing children matched for mental age, both infants and toddlers with Down syndrome need less stimulation to elicit a response (i.e., have a lower threshold for stimulation), (Bridges 1982, Gunn 1985).
4. Compared with typically developing children matched for chronologic age, 2 1/2- to 3-year-old children with Down syndrome need higher levels of stimulation to elicit a response (Gunn 1985, Huntington 1987, Marcovitch 1986, Vaughn 1994).
5. Compared with typically developing children matched for either chronologic or mental age, children with Down syndrome are more approachable (Marcovitch 1986).
6. Compared with typically developing children matched for either chronologic or mental age, children with Down syndrome are less adaptable in new situations (Vaughn 1994).
7. Compared with typically developing children matched for chronologic age, children with Down syndrome:
   - Are more likely to be seen as having “easy” temperaments
   - Are less likely to be considered “difficult” or “slow to warm up” (Marcovitch 1987)
8. Infants with Down syndrome and typically developing infants who are matched for mental age appear to have similar temperaments in terms of level and intensity of activity, adaptability, distractibility, rhythmicity of behaviors, and mood (Bridges 1982).
9. Compared with typically developing children matched for either chronologic or mental age, children with Down syndrome who are 2 to 3 years old tend to show:
   - More rhythmicity in behaviors
   - Less intensity of behaviors
   - A more positive mood (Gunn 1985)
10. Children with Down syndrome age 2 to 3 years old and typically developing infants matched for mental age appear to have similar

temperaments in terms of their levels of activity, adaptability, and distractibility (Gunn 1985, Huntington 1987, Marcovitch 1986).

F. Evidence on Development of Adaptive/Self-Help Skills

There were no studies that met the panel's criteria for adequate evidence on developmental characteristics that used adaptive/self-help skills as a primary focus. However, because developmental skills are interrelated, various aspects of adaptive/self-help development are addressed in studies meeting the criteria for evidence for other developmental domains, such as cognition and motor development.

In developing conclusions on this topic, the panel also used some information from sources that did not meet the criteria for adequate evidence. Specifically, information from Cunningham (1996) and Wolery (1989) was used by the panel to help construct panel conclusions about the development of adaptive/self-help skills for children with Down syndrome and typically developing children.

Panel Conclusions (Development of Adaptive/Self-Help Skills)

While young children with Down syndrome develop individual adaptive/self-help skills in a progression similar to typically developing children, self-help skills in children with Down syndrome tend to develop later than in typically developing children. Because of the interrelatedness of developmental domains, these delays in self-help are probably related to delays in other domains, such as cognitive and motor.

HEALTH ASSESSMENT RESEARCH

Thyroid and Growth Hormone Studies

This section reviews the evidence about thyroid and growth hormone function in young children with Down syndrome. There were three studies that met the panel's criteria for adequate evidence about this topic, two studies of thyroid function and one study of growth hormone.

Studies Meeting Criteria for Evidence

1. **Castells,** S., Beaulieu, I., Torrado, C., Wisniewski, K. E., Zarny, S., and Gelato, M. C. Hypothalamic versus pituitary dysfunction in Down's syndrome as cause of growth retardation. *Journal of Intellectual Disability Research* 1996; 40 [6]: 509-517.

2. **Cutler,** A. T., Benezra-Obeiter, R., and Brink, S. J. Thyroid function in young children with Down syndrome. *American Journal of Diseases of Children* 1986; 140[5]: 479-483.

3. **Sharav,** T., Landau, H., Zadik, Z., and Einarson, T. R. Age-related patterns of thyroid-stimulating hormone response to thyrotropin-releasing hormone stimulation in Down syndrome. *American Journal of Diseases of Children* 1991; 145[2]: 172-175.

Panel Conclusions (Thyroid and Growth Hormone Studies)

Thyroid function

1. Of the children in the Down syndrome group who ranged in age from 4 months to 3 years: (Cutler 1986)
   - Twenty-seven percent had elevated TSH and normal T_4 values
   - Ten percent had significant thyroid disease
2. Compared with typically developing children matched for chronologic age, children with Down syndrome ranging in age from 1 to 3 years of age:
   - Have similar levels of T_4
   - Have elevated levels of TSH when under 1 year of age (transient elevation) (Cutler 1986)
3. Children with Down syndrome ranging from 1 to 7 years of age, compared with typically developing children matched for chronologic age:
   - Have higher TSH levels
   - Have similar T_3 and T_4 levels
   - Have similar thyroid antibody results (negative)
   - Exhibit similar differences in basal and peak THS levels between the two younger age groups (less than 1 year and 1 to 3 years of age) compared with the oldest age group (3 to 7 years of age) (Sharav 1991)

Growth hormone function and growth retardation

4. Children with Down syndrome ranging from 1 to 5 years of age, compared with typically developing children, tend to:
   - Have smaller heads (microcephaly)
   - Have growth retardation (Castells 1996)

5. Compared with typically developing children, children with Down syndrome (from age 1 to 5 years) have an abnormally low response of serum GH concentration when given the pharmacological stimuli of levodopa and clonidine. This is an indication of hypothalamic dysfunction (Castells 1996).

6. Compared with typically developing children, children with Down syndrome (from age 1 to 5 years) have a normal GH response when given GHRH. This indicates normal pituitary function (Castells 1996).

INTERVENTION RESEARCH

Evaluating the Efficacy of Interventions

A. Behavioral/Educational Interventions

There were eight studies on this topic that met the panel's criteria for adequate evidence about efficacy of the intervention method.

Studies Meeting Criteria for Evidence

Interventions Focused on Child

1. **Connolly,** B. and Russell, F. Interdisciplinary early intervention program. *Physical Therapy* 1976; 56: 155-158.

2. **Connolly,** B., Morgan, S., Russell, F. F., and Richardson, B. Early intervention with Down syndrome children: Follow-up report. *Physical Therapy* 1980; 60[11]: 1405-1408.

3. **Connolly,** B. H., Morgan, S., and Russell, F. F. Evaluation of children with Down syndrome who participated in an early intervention program: Second follow-up study. *Physical Therapy* 1984; 64[10]: 1515-1519.

4. **Connolly,** B. H., Morgan, S. B., Russell, F. F., and Fulliton, W. L. A longitudinal study of children with Down syndrome who experienced early intervention programming. *Physical Therapy* 1993; 73[3]: 170-181.

5. **Piper,** M. C. and Pless, I. B. Early intervention for infants with Down syndrome: A controlled trial. *Pediatrics* 1980; 65[3]: 463-468.

6. **Sanz,** M. T. and Menendez, J. A Study of the effect of age of onset of treatment on the observed development of Down's syndrome babies. *Early Child Development and Care* 1996; 118: 93-101.

7. **Schoen,** S. F., et al. An examination of two prompt fading procedures and opportunities to observe in teaching handicapped preschoolers self-help skills. *Journal of the Division for Early Childhood* 1988; 12[4]: 349-358.

Interventions Focused on Parent

8. **Bidder,** R. T., Bryant, G., and Gray, O. P. Benefits to Down's syndrome children through training their mothers. *Archives of Diseases in Childhood* 1975; 50: 383-386.

9. **Bruder,** M. B. Parent-to-parent teaching. *American Journal of Mental Deficienc*y 1987; 91[4]: 435-438.

10. **Kysela,** G., Hillyard, A., McDonald, L., and Ahlsten-Taylor, J. Early intervention: Design and evaluation. p. 341-388. In *Language Intervention Series: Vol.6, Early Language: Acquisition and intervention.* Schiefelbusch, R. L. and Bricker, D. D. (eds.). Baltimore, MD: University Park Press, 1981.

11. **Sloper,** P., Glenn, S. M., and Cunningham, C. C. The effect of intensity of training on sensori-motor development in infants with Down's syndrome. *Journal of Mental Deficiency Research* 1986; 30 [2]: 149-162.

Panel Conclusions (Behavioral/Educational Interventions)

Interventions focused on child

1. Starting intervention programs early (within the first month after birth) appears to be more beneficial than starting later in infancy (Sanz 1996).

2. Early educational programs individualized to the needs of the child and family can benefit young children with Down syndrome (Bidder 1975, Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981).

3. Children with Down syndrome generally show a decline in standardized scores of development (such as developmental quotients) as they get older (Carr 1970). There is some evidence that participation in early intervention programs may reduce these declines in cognitive and social functioning scores (Connolly 1976/Connolly 1980/Connolly 1984/Connolly 1993, Kysela 1981).

4. Instructional methods using techniques based from learning theory (such as graduated guidance, decreasing assistance, and other prompt fading

procedures) can be effective in teaching young children with Down syndrome (Bidder 1975, Bruder 1987, Schoen 1988, Sloper 1986).

Interventions focused on parent training

5. A six-month program of one-hour biweekly therapy sessions combined with instructions to parents for follow-up may not be an intensive enough program to reduce the declines in developmental quotients for young children with Down syndrome (Piper 1980).
6. Training parents as primary interventionists can result in improvements in their teaching skills (Bruder 1987).
7. Training parents, either as part of an intervention program or as primary interventionists, can result in improvements in their children's performance (Bidder 1975, Bruder 1987, Kysela 1981, Sanz 1996, Sloper 1986).
8. Effective elements in training parents include verbal instruction, practice, feedback, and teaching the methods to other parents (Bruder 1987).

B. Communication/Language Interventions

There were three studies on this topic that met the panel's criteria for adequate evidence about efficacy of the intervention method.

Studies Meeting Criteria for Evidence

Interventions focused on child

1. **Poulson,** C. L. Operant conditioning of vocalization rate of infants with Down syndrome. *American Journal of Mental Retardation* 1988; 93[1]: 57-63.

Interventions focused on parent

2. **Girolametto,** L. E. Improving the social-conversational skills of developmentally delayed children: an intervention study. *Journal of Speech and Hearing Disorders* 1988; 53[2]: 156-167.
3. **Jago,** J. L., Jago, A. G., and Hart, M. An evaluation of the total communication approach for teaching language skills to developmentally delayed preschool children. *Education and Training of the Mentally Retarded* 1984; 19[3]: 175-182.

Panel Conclusions (Communication/Language Interventions)

Interventions focused on child

1. For an infant with Down syndrome, a parent can increase the infant's vocalization rate by smiling, making eye contact, and playing with the infant during or immediately following a vocalization. The parent's social behavior serves as a reinforcer (Poulson 1988).

Interventions focused on parent training

2. Interventions that involve training parents in a social-conversational language program can result in improvements in parent communication patterns when interacting with their children (Girolametto 1988).
3. For young children with Down syndrome and other developmental delays, training parents to modify their communication patterns can result in improvements in children's communication abilities such as turn-taking and responsiveness (Girolametto 1988).
4. For young children with Down syndrome and other developmental delays, more extensive training of the children and their parents in sign language can result not only in a significant increase in the number of signs acquired by the children but also in improvements in their expressive language scores on a standardized test (Jago 1984).

C. Motor Therapy Intervention Approaches

There were two studies on this topic that met the panel's criteria for adequate evidence about efficacy of the interventions for manual therapy approaches.

Studies Meeting Criteria for Evidence

1. **Harris,** S. R. Effects of neurodevelopmental therapy on motor performance of infants with Down's syndrome. *Developmental Medicine and Child Neurology* 1981; 23[4]: 477-483.
2. **Harris,** S. R. Physical therapy and infants with Down's syndrome: The effects of early intervention. *Rehabilitation Literature* 1981A; 42[11-12]: 339-343.
3. **Lydic,** J. S., Windsor, M. M., Short, M. A., and Ellis, T. A. Effects of controlled rotary vestibular stimulation on the motor performance of infants with Down's syndrome. *Physical and Occupational Therapy in Pediatrics* 1985; 5[2/3]: 93-118.

Panel Conclusions (Motor Therapy Intervention Approaches)

1. Motor therapy based on the neurodevelopmental treatment (NDT) approach may be effective in improving motor performance in young children with Down syndrome if this improvement is measured by the number of individualized therapy objectives attained (Harris 1981/Harris 1981A).
2. Adequate research evidence was not found to demonstrate the effectiveness of interventions based on either NDT or vestibular stimulation for improving outcomes on standardized tests of motor development in young children with Down syndrome (Harris 1981/Harris 1981A, Lydic 1985).

D. Oral-Motor Interventions

There were two studies on this topic that met the panel's criteria for adequate evidence about efficacy of intervention methods.

Studies Meeting Criteria for Evidence

1. **Carlstedt,** K., Dahllof, G., Nilsson, B., and Modeer, T. Effect of palatal plate therapy in children with Down syndrome: A 1-year study. *Acta Odontologia Scandinavica* 1996; 54[2]: 122-125.
2. **Purdy,** A. H., Deitz, J. C., and Harris, S. R. Efficacy of two treatment approaches to reduce tongue protrusion of children with Down syndrome. *Developmental Medicine and Child Neurology* 1987; 29[4]: 469-476.

Panel Conclusions (Oral-Motor Interventions)

1. For young children with Down syndrome, palatal plate therapy (used for 1/2 to 1 hour a day for 9 to 12 months) in combination with regular oral-motor exercises can be effective in reducing oral-motor dysfunction, including reducing inactive tongue protrusion and improving mouth closure (Carlstedt 1996).
2. Oral-motor treatment based on either NDT principles or behavior modification techniques can be used to reduce tongue protrusions in young children with Down syndrome (Purdy 1987).

E. Health-Related Interventions (Vitamin Therapy)

There were two studies on this topic that met the panel's criteria for adequate evidence about efficacy, and both of these evaluated vitamin and/or mineral supplement therapy.

Studies Meeting Criteria for Evidence

1. **Bidder,** R. T., Gray, P., Newcombe, R. G., Evans, B. K., and Hughes, M. The effects of multivitamins and minerals on children with Down syndrome. *Developmental Medicine and Child Neurology* 1989; 31[4]: 532-537.

2. **Coleman,** M., Sobel, S., Bhagavan, H. N., Coursin, D., Marquardt, A., Guay, M., and Hunt, C. A double blind study of vitamin B6 in Down's syndrome infants. Part 1 - Clinical and biochemical results. *Journal of Mental Deficiency Research* 1985; 29[3]: 233-240.

3. **Frager,** J., Barnet, A., Weiss, I., and Coleman, M. A double blind study of vitamin B6 in Down's syndrome infants. Part 2 - Cortical auditory evoked potentials. *Journal of Mental Deficiency Research* 1985; 29[3]: 241-246.

Panel Conclusions (Vitamin Therapy)

1. High dose vitamin/mineral supplements do not appear to improve the developmental progress of young children with Down syndrome and may have detrimental side effects (Bidder 1989).

2. High dose vitamin/mineral supplements have frequent undesirable side effects, such as flushing, tightness of the skin, and vomiting (Bidder 1989).

3. Long-term administration of vitamin B6 does not appear to improve the rate of development of young children with Down syndrome (Coleman 1985/Frager 1985).

APPENDIX C: TESTS FOR IDENTIFICATION AND ASSESSMENT OF YOUNG CHILDREN WHO HAVE DOWN SYNDROME

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Vineland Adaptive Behavior Scales (VABS) 220

Ages and Stages Questionnaires (ASQ)

Type of Test	Set of 11 developmental questionnaires containing 30 items each. Sent periodically to parents of children who show potential developmental problems.
Purpose	To identify children who need further testing and possible referral for developmental evaluation and services.
Age Range	4 months to 48 months. Testing is recommended at 4, 8, 12, 16, 20, 24, 30, 36, and 48 months.
Components	Areas screened include gross motor, fine motor, communication, personal-social, and problem solving. There are 3 versions.
Scoring	Parent responses to questions with “yes,” “sometimes,” or “not yet” are converted to scores used to monitor the child’s development.
Time	Approximately 20 minutes to complete questionnaire.
Standardization	The test was standardized on a sample of 2,008 children (53% were male; the occupational and ethnic statuses of families were diverse). The sample included children with disabilities and those at environmental or medical risk. Information on reliability and validity testing is included in the manual.
Training	Parents use their observations in a natural environment to respond to questionnaire.
Other Versions	Spanish

Alberta Infant Motor Scale (AIMS)

Type of Test	A standardized assessment of infant development.
Purpose	Measures gross motor maturation in infants. Identifies infants whose motor performance is delayed or aberrant.
Age Range	Birth to 18 months (independent walking)
Components	Assesses 58 items for infants at increased risk for motor problems. The focus of the assessment is on postural control relative to four postural positions: supine, prone, sitting, and standing.
Scoring	Scored through observation with little or no handling.
Time	15 minutes
Standardization	Based on a sample of 2,400 infants
Training	Physical therapists observe the infants

Battelle Developmental Inventory (BDI)

Type of Test	Criterion-based and norm-referenced with hearing norms, using verbal instructions and nonvocal responses. This is a measure of developmental skills across five domains. A screening test with 28% of the items is included. Allows for multisource assessment.
Purpose	To identify handicapped children, strengths and weaknesses of nonhandicapped children, appropriate instructional plans for individual children, and monitor child's progress.
Age Range	Birth to 8 years
Components	Test has one form with five domains: personal-social, adaptive, motor, communication, and cognitive. Some testing materials are supplied with manual.
Scoring	Items are scored from 0-2 based on interviews of caregivers or teachers, observation, and/or task performance. Emerging skills are included. Scores include percentile ranks for the overall test, domains, and some sub-domains. Standard scores can be obtained for conversion of percentile scores.
Time	1-2 hours for entire test, 0-30 minutes for screening test, 30 minutes for cognitive domain.
Standardization	A total of 800 children were selected based on region, gender, race, and urban/rural residency according to 1981 census statistics.
Training	Not specified

Bayley Scales of Infant Development II (BSID-II) (Second Edition 1993)

Type of Test	A standardized assessment of infant development.
Purpose	The test is intended to measure a child's level of development in three domains: cognitive, motor and behavioral.
Age Range	Birth to 42 months
Components	The BSID-II consists of three scales: mental, motor, and behavior rating scales. The test contains items designed to identify young children at risk for developmental delay.
Scoring	An "item set" based on age is presented in a specific order and scored with some examiner flexibility. Standardized scores are reported for either the Mental Development Index (MDI) or the Performance Development Index (PDI).
Time	From 30 minutes to 60 minutes
Standardization	BSID normative data reflects the U.S. population in terms of race/ethnicity, infant's gender, education level of parents, and demographic location of the infant. The Bayley was standardized on 1,700 infants, toddlers, and preschoolers between 1 and 42 months of age. Norms were established using samples that did not include disabled, premature, and other at-risk children. Corrected scores may be used for these higher risk groups, but their use is controversial.
Training	Appropriate training and experience are necessary to correctly administer and score the assessment.

Carolina Curriculum for Infants and Toddlers with Special Needs (CCITSN)

Purpose	A curriculum-based assessment used to determine curricular interventions for infants and toddlers with mild to severe special needs.
Age Range	Birth to 24-month level of development
Components	Curriculum is divided into 26 teaching sequences that cover the 5 developmental domains. Specific activities and adaptations appropriate for diverse functional levels and disabilities, including perceptual impairment and motor delay, are included. Instructional activities are process oriented, providing suggestions for incorporating activities into daily care and modifications for infants with motor, visual, or hearing impairments.
Scoring	Items scored pass-fail. Based on examiner's judgment, infant's performance may also be scored as partially successful. Child must successfully perform an item for 3 of 5 trials to reach teaching criterion.
Time	Not specified
Standardization	Criterion referenced. Scores not norm-referenced. Field-tested curriculum and assessment with details provided. Inter-rater reliability of 96.9% agreement reported for first edition.
Training	Formal training not required. Designed to be administered by professionals from numerous disciplines.

Functional Independence Measure for Children (WeeFIM)

Purpose	Functional assessment for infants to determine the severity of a disability and the amount of assistance required.
Age Range	6 months to 7 years
Components	Measures a range of 18 functional abilities based on self-care, sphincter control, transfers, locomotion, communication, and social cognition.
Scoring	Seven level ordinal scales rated from complete dependence to complete independence, based on caregiver interview, direct observation, or a combination of both.
Time	Not specified
Standardization	Not specified
Training	Training program for examiners is required, which included lectures, rating videotape, and completing three written case studies.

Gesell Developmental Schedules (GDS) - Revised

Type of Test	A standardized test of a child's general development.
Purpose	Intended to assess a child's general development. Originally designed as a diagnostic developmental assessment of the integrity of the child's nervous system.
Age range	Birth to 72 months Uses age equivalents over 72 months
Components	Test components include language, fine and gross motor, cognitive, and personal-social domains. Combines parent history and formal behavioral examination.
Scoring	Results can be expressed as developmental quotient (DQ) in each of five domains (gross motor, fine motor, adaptive, language, and personal-social).
Time	Not specified
Standardization	Has a normative reference group of 927 low birth weight, preterm infants. Revised and re-normed in 1980. Normative values from the Gesell have been integrated into other assessment instruments (such as the Ages and Stages Questionnaire).
Training	Designed to be administered by physicians and others knowledgeable in central nervous system development.

Hawaii Early Learning Profile (HELP)

Purpose	Designed as a family-centered assessment instrument intended to facilitate comprehensive assessment by an interdisciplinary team.
Age Range	Children who function at or below 36 months of age
Components	Test based on normal developmental sequence. Seven functional areas are assessed using a checklist of 685 developmental items. Functional areas include regulatory/sensory organization, cognitive, language, gross and fine motor, social-emotional, and self-help.
Scoring	Infant's performance on an item is scored as pass-fail or partially successful based on examiner's judgment. Scores are used with qualitative description of the child's developmental skills and behaviors to determine approximate developmental level within major developmental domains.
Time	Not specified
Standardization	Field-tested the curriculum and assessment, but details not provided. Not standardized, but uses developmental sequences from standardized tests and developmental scales.
Training	Assessments designed to be administered by professionals from different disciplines. Formal training not required.

Leiter Performance Scale and Leiter International Performance Scale (LIPS)

Purpose	Measures intelligence through testing of nonverbal items. Serves as supplementary measure of intelligence.
Age Range	24 months to 20 years
Components	Based on 2 nationally standardized test batteries: a visualization and reasoning domain battery, and a reasoning domain battery. Tests are designed to be used with motor impaired children and instructions are nonverbal.
Scoring	Uses age-scale format. Provides IQs by the ratio method.
Time	30-35 minutes to administer
Standardization	Norms outdated and there are concerns about standardization since there is limited information about reliability and validity.
Training	For use by professionals who have been trained in its use.

Peabody Developmental Motor Scales (PDMS)

Purpose	Test able to discriminate between motor-delayed and typically developing children. Evaluates changes over time and aids in treatment and planning.
Age Range	Newborn to 7 years
Components	Functional items well defined. Lack of items related to quality of movement is main drawback to test for its use in assessing motor performance in cerebral palsy.
Scoring	Raw score (or scaled score for children with handicaps) can be calculated.
Time	Not specified
Standardization	Assessed 617 newborn to 7-year-old children in U.S
Training	Not specified

Pediatric Evaluation of Disability Inventory (PEDI)

Purpose	A judgment-based functional assessment that sample content in domains of self-care, mobility, and social function. Functional assessment of infant and toddler through interview with parents.
Age Range	Test is designed for children between ages of 6 months and 7.5 years, but can be used for older children if functional abilities fall below those expected of typically developing 7-year-old children.
Components	Measures both capability and performance of 197 functional skill items.
Scoring	The level of assistance to complete specific activities is measured.
Time	Direct administration takes 20 to 30 minutes. Administration by parent report or interview can take up to 45 minutes.
Standardization	Standardized on 412 children and families stratified by age, gender, race-ethnicity, parent education, community size, and other socio-economic factors.
Training	Training requirements included in the manual.

Test of Sensory Function in Infants (TSFI)

Purpose	Diagnostic tool designed to assess sensory processing and reactivity in infants with regulatory disorder, developmental delays, or at risk for later learning and sensory processing disorder (i.e., high-risk, premature infants).
Age Range	4 to 18 months
Components	Includes 5 sub-domains including reactivity to deep pressure, adaptive motor functions, visual tactile integration, oculo-motor control, and reactivity to vestibular stimulation. Observations elicited through structured facilitation of response to select sensory stimuli. Can be administered while infant is positioned on parent's lap.
Scoring	Scoring sheet is provided for individual items to reflect the infant's profile relative to each subtest. Each test is scored as either normal, at risk, or deficient. Examiner must follow verbal directions and administer exactly as described in test manual. Items must be given in the specified order. Parent can be coached to assist in the event of stranger anxiety.
Time	Approximately 20 minutes
Standardization	Criterion referenced test. Based on a sample of 288 normal infants, 27 delayed infants, and 27 with regulatory disorders.
Training	Examiners should become familiar with administration and scoring prior to use. Two hours of practice is the recommended minimum amount.

Toddler and Infant Motor Evaluation (TIME)

Purpose	Measures quality of movements in children with suspected motor dysfunction. It provides information to be used in treatment planning and to measure change over time.
Age Range	Birth to 42 months
Components	Content domains measured include mobility, stability, organization, and dysfunctional positions. Incorporates flexible administrative format in which examiner observes child's spontaneous movements and parent does necessary manipulation.
Scoring	Spontaneous movements are recorded for first 10 seconds that child spends in each starting position: supine, prone, sitting, quadruped, and standing. The sequence of positions assumed is recorded, as are any abnormalities. Some evoked movements are also scored. Positioning and handling of child done by parent, with only verbal cues given by therapist.
Time	15 – 30 minutes
Standardization	Pilot-tested on sample of over 600 children, including 133 infants and toddlers with motor delays stratified by major demographic variables. Standard scores will be available.
Training	Appears easy to administer, instructions are clear. Unclear how much training needed for final form; however, tester will probably need to have significant experience in developmental testing.

Vineland Adaptive Behavior Scales (VABS)	
Type of Test	Assesses adaptive skills (personal and social sufficiency) from birth to adulthood.
Purpose	To assess communication, daily living skills, socialization, and motor skills domains.
Age Range	Newborn to 18 years
Components	Three forms are available: the Interview Edition Survey with 297 items, the Expanded Form with 577 items, and the Classroom Edition with 244 items.
Scoring	A respondent (a parent, a teacher, or another professional) who knows the individual well answers behavior-oriented questions about the individual's adaptive behavior.
Results	Can be expressed as a standard score, percentiles, or age equivalents in each domain, as well as in the form of an Adaptive Behavior Composite.
Time	Approximately 90 minutes
Standardization	The Interview Edition Survey and Expanded Form were standardized on 3,000 individuals from birth through 18 years of age. Separate norms are available for children with mental retardation, emotional disorders, and physical handicaps. An additional 3,000 children ranging in age from 3 to 12 years served as the normative group for the Classroom Edition.
Training	Administration requires appropriate training and professional experience.

APPENDIX D: EARLY INTERVENTION PROGRAM INFORMATION

New York State

D-1: EARLY INTERVENTION PROGRAM DESCRIPTION

The Early Intervention Program is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help families:

- Learn the best ways to care for their child
- Support and promote their child's development
- Include their child in family and community life

Early Intervention services can be provided anywhere in the community, including:

- A child's home
- A child care center or family day care home
- Recreational centers, playgroups, playgrounds, libraries, or any place parents and children go for fun and support
- Early childhood programs and centers

Parents help decide:

- What are appropriate early intervention services for their child and family
- The outcomes of early intervention that are important for their child and family
- When and where their child and family will get early intervention services
- Who will provide services to their child and family

Early Intervention Officials (EIO)

In New York State, all counties and the City of New York are required by public health law to appoint a public official as their Early Intervention Official.

The EIO is the person in the county responsible for:

- Finding eligible children

- Making sure eligible children have a multidisciplinary evaluation
- Appointing an initial service coordinator to help families with their child's multidisciplinary evaluation and Individualized Family Service Plan (IFSP)
- Making sure children and families get the early intervention services included in their IFSPs
- Safeguarding child and family rights under the Program

The EIO is the "single point of entry" for children into the Program. This means that all children under three years of age who may need early intervention services must be referred to the EIO. In practice, Early Intervention Officials have staff who are assigned to take child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official (see Step 1 of Early Intervention Steps, page 229). Sometimes, someone else will be the first to raise a concern about a child's development. New York State public health law requires certain professionals (primary referral sources) to refer infants and toddlers to the Early Intervention Official if a problem with development is suspected. However, no professional can refer a child to the EIO if the child's parent says no to the referral.

Service Coordinators

There are two types of service coordinators in New York State: an initial service coordinator and an ongoing service coordinator. The initial service coordinator is appointed by the Early Intervention Official. The initial service coordinator helps with all the steps necessary to get services, from the child's multidisciplinary evaluation to the first Individualized Family Service Plan (IFSP).

Parents are asked to choose an ongoing service coordinator as part of the first IFSP. The main job of the ongoing service coordinator is to make sure the child and family get the services included in the IFSP. The ongoing service coordinator will also help change the IFSP when necessary and make sure the IFSP is reviewed on a regular basis. Parents may choose to keep the initial service coordinator, or they can choose a new person to be the ongoing service coordinator.

Eligibility

Children are eligible for the Early Intervention Program if they are under three years old AND have a disability OR developmental delay. A disability means

that a child has a diagnosed physical or mental condition that often leads to problems in development (such as Down syndrome, autism, cerebral palsy, vision impairment, or hearing impairment).

A developmental delay means that a child is behind in at least one area of development, including:

- Physical development (growth, gross and fine motor abilities)
- Cognitive development (learning and thinking)
- Communication (understanding and using words)
- Social-emotional development (relating to others)
- Adaptive development (self-help skills, such as feeding)

A child does not need to be a U.S. citizen to be eligible for services. And, there is no income "test" for the Program. The child and family do have to be residents of New York State to participate in the Early Intervention Program.

How is Eligibility Decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to determine if they are eligible for services. The multidisciplinary evaluation also helps parents to better understand their child's strengths and needs and how early intervention can help.

A child who is referred because of a diagnosed condition that often leads to developmental delay, such as Down syndrome, will always be eligible for early intervention services.

If a child has a diagnosed condition, he or she will still need a multidisciplinary evaluation to help plan for services. If a child has a delay in development and no diagnosed condition, the multidisciplinary evaluation is needed to find out if the child is eligible for the Program. A child's development will be measured according to the "definition of developmental delay" set by New York State.

Services

Early intervention services are:

- Aimed at meeting children's developmental needs and helping parents take care of their children
- Included in an Individualized Family Service Plan (IFSP) agreed to by the parent and the Early Intervention Official

Early intervention services include:

- Assistive technology services and devices
- Audiology
- Family training, counseling, home visits, and parent support groups
- Medical services for diagnostic or evaluation purposes only
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Social work services
- Special instruction
- Speech-language pathology
- Vision services
- Health services needed for children to benefit from other early intervention services
- Transportation to and from early intervention services

Provision of Services

Only qualified professionals, i.e., individuals who are licensed, certified, or registered in their discipline and approved by New York State, can deliver early intervention services. All services can be provided using any of the following service models:

- Home- and community-based visits. In this model, services are given to a child and/or parent or other family member or caregiver at home or in the community (such as a relative's home, child care center, family day care home, playgroup, library story hour, or other places parents go with their children).

- Facility- or center-based visits. In this model, services are given to a child and/or parent or other family member or caregiver where the service provider works (such as an office, a hospital, a clinic, or early intervention center).
- Parent-child groups. In this model, parents and children get services together in a group led by a service provider. A parent-child group can take place anywhere in the community.
- Family support groups. In this model, parents, grandparents, siblings, or other relatives of the child get together in a group led by a service provider for help and support and to share concerns and information.
- Group developmental intervention. In this model, children receive services in a group setting led by a service provider or providers without parents or caregivers present. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and can take place anywhere in the community.

REIMBURSEMENT

All services are at no cost to families. The program accesses Medicaid and commercial third party insurance when parents' policies are regulated by the state. County and state funds cover the costs of services.

For more information about the New York State laws and regulations and administrative guidance documents that apply to early intervention services, contact the Bureau of Early Intervention.

New York State Department of Health
Bureau of Early Intervention
Corning Tower Building, Room 287
Albany, NY 12237-0660

518/473-7016

http://www.nyhealth.gov/community/infants_children/early_ intervention/index.htm

bei@health.state.ny.us

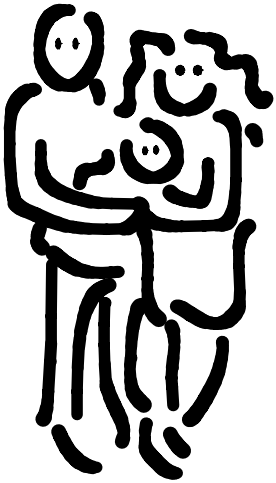
Family Concern

1. Referral *(unless parent objects)*

- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program
- Child referred to EIO within 2 days of identification
- Early Intervention Official assigns Initial Service Coordinator

2. Initial Service Coordinator

- Provide information about EIP
- Inform family of rights
- Review list of evaluators
- Obtain insurance/Medicaid information
- Obtain other relevant information



3. Evaluation*

- Determine eligibility
- Family assessment, optional
- Gather information for IFSP
- Summary and report submitted prior to IFSP

4. The IFSP Meeting* *(if child is eligible)*

- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
- Family and EIO agree to IFSP
- Identify Ongoing Service Coordinator
- EIO obtains social security number(s)

**May access due process procedures*

6. Transition

- Plan for transition included in IFSP
- Transition to:
  - services under Section 4410 of Education Law (3-5 system)

  OR
  - other early childhood services, as needed

Areas of Development

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development

5. IFSP – Review Six Months /Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies, and/or services
- If parent requests, may review sooner:
  - If parent requests an increase in services, EIO may ask for independent evaluation

Early Intervention Services*

- assistive technology devices and services
- audiology
- family training, counseling, home visits and parent support groups
- medical services only for diagnostic or evaluation purposes
- nursing services
- nutrition services
- occupational therapy
- physical therapy
- psychological services
- service coordination
- social work services
- special instruction
- speech-language pathology
- vision services
- health services
- transportation and related costs

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.

Revised 12/04

THE IFSP MEETING

D-2: OFFICIAL EARLY INTERVENTION PROGRAM DEFINITIONS

These definitions are excerpted from New York State Code of Rules and Regulations, §69-4.1, §69-4.10, and §69-4.11. For a complete set of the regulations governing the Early Intervention Program, contact the New York State Department of Health Bureau of Early Intervention at (518) 473-7016 or visit the Department's website: http://www.nyhealth.gov/community/infants_children/early_intervention/index.htm.

Sec. 69-4.10 Service Model Options

(a) The Department of Health, state early intervention service agencies, and early intervention officials shall make reasonable efforts to ensure the full range of early intervention service options are available to eligible children and their families.

(1) The following models of early intervention service delivery shall be available:

(i) home and community based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at the child's home or any other natural environment in which children under three years of age are typically found (including day care centers and family day care homes);

(ii) facility-based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at an approved early intervention provider's site;

(iii) parent-child groups: a group comprised of parents or caregivers, children, and a minimum of one appropriate qualified provider of early intervention services at an early intervention provider's site or a community-based site (e.g. day care center, family day care, or other community settings);

(iv) group developmental intervention: the provision of early intervention services by appropriate qualified personnel to a group of eligible children at an approved early intervention provider's site or in a community-based setting where children under three years of age are typically found (this group may also include children without disabilities); and

(v) family/caregiver support group: the provision of early intervention services to a group of parents, caregivers (foster parents, day care staff, etc.) and/or siblings of eligible children for the purposes of:

(a) enhancing their capacity to care for and/or enhance the development of the eligible child; and

(b) providing support, education, and guidance to such individuals relative to the child's unique developmental needs.

Sec. 69-4.1 Definitions

(b) *Assessment* means ongoing procedures used to identify:

(1) the child's unique needs and strengths and the services appropriate to meet those needs; and

(2) the resources, priorities, and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.

(g) *Developmental delay* means that a child has not attained developmental milestones expected for the child's chronological age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social/emotional, or adaptive development.

(1) A developmental delay for purposes of the Early Intervention Program is a developmental delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures, and/or instruments and documented as:

(i) a twelve month delay in one functional area; or

(ii) a 33% delay in one functional area or a 25% delay in each of two areas; or

(iii) if appropriate standardized instruments are individually administered in the evaluation process, a score of at least 2.0 standard deviations below the mean in one functional area or score of at least 1.5 standard deviation below the mean in each of two functional areas.

(ag) *Parent* means a parent by birth or adoption, or person in parental relation to the child. With respect to a child who is a ward of the state, or a child who is not a ward of the state but whose parents by birth or adoption are unknown or unavailable and the child has no person in parental relation, the term "parent" means a person who has been appointed as a surrogate parent for the child in accordance with Section 69-4.16 of this subpart. This term does not include the state if the child is a ward of the state.

(aj) *Qualified personnel* are those individuals who are approved as required by this subpart to deliver services to the extent authorized by their licensure, certification, or registration, to eligible children and have appropriate licensure, certification, or registration in the area in which they are providing services, including:

Qualified Personnel:

(1) audiologists;

(2) certified occupational therapy assistants;

(3) licensed practical nurses, registered nurses, and nurse practitioners;

(4) certified low vision specialists;

(5) occupational therapists;

(6) orientation and mobility specialists;

(7) physical therapists;

(8) physical therapy assistants;

(9) pediatricians and other physicians;

(10) physician assistants;

(11) psychologists;

(12) registered dieticians;

(13) school psychologists;

(14) social workers;

(15) special education teachers;

(16) speech and language pathologists and audiologists;

(17) teachers of the blind and partially sighted;

(18) teachers of the deaf and hearing handicapped;

(19) teachers of the speech and hearing handicapped;

(20) other categories of personnel as designated by the Commissioner.

(al) *Screening* means a process involving those instruments, procedures, family information and observations, and clinical observations used by an approved evaluator to assess a child's developmental status to indicate what type of evaluation, if any, is warranted.

Sec. 69-4.11 Individualized Family Service Plan

(10) The IFSP shall be in writing and include the following:

(i) a statement, based on objective criteria, of the child's present levels of functioning in each of the following domains: physical development, including vision and hearing; cognitive development;

communication development; social or emotional development; and adaptive development;

(ii) a physician's or nurse practitioner's order pertaining to early intervention services which require such an order and which includes a diagnostic statement and purpose of treatment;

(iii) with parental consent, a statement of the family's strengths, priorities and concerns that relate to enhancing the development of the child;

(iv) a statement of

(a) the major outcomes expected to be achieved for the child and the family, including timelines, and

(b) the criteria and procedures that will be used to determine whether progress toward achieving the outcomes is being made and whether modifications or revisions of the outcomes or services is necessary;

D-3: TELEPHONE NUMBERS OF MUNICIPAL EARLY INTERVENTION PROGRAMS

The following telephone numbers were up to date at the time this document was published. Please visit our Web page for updates at: www.nyhealth.gov/community/infants_children/early_intervention/index.htm.

Albany	518-447-4820
Allegany	585-268-9250
Broome	607-778-2851
Cattaraugus	716-373-8050
Cayuga	315-253-1459
Chautauqua	716-753-4491
Chemung	607-737-5568
Chenango	607-337-1729
Clinton	518-565-4798
Columbia	518-828-4278 Ext. 1305
Cortland	607-756-3439
Delaware	607-746-3166
Dutchess	845-486-3518
Erie	716-858-6161
Essex	518-873-3500
Franklin	518-481-1709
Fulton	518-736-5720
Genesee	585-344-2580 Ext. 5000
Greene	518-719-3600
Hamilton	518-648-6141
Herkimer	315-867-1430
Jefferson	315-785-3283
Lewis	315-376-5401
Livingston	585-243-7299
Madison	315-366-2361
Monroe	585-753-5274
Montgomery	518-853-3531
Nassau	516-227-8661
New York City	212-219-5213

Niagara	716-278-1991
Oneida	315-798-5249
Onondaga	315-435-3230
Ontario	585-396-4439
Orange	845-291-2333
Orleans	585-589-2777
Oswego	315-349-3510
Otsego	607-547-6474
Putnam	845-278-6014 Ext. 2170
Rensselaer	518-270-2665
Rockland	845-364-2626
Saratoga	518-584-7460 Ext. 390
Schenectady	518-386-2815
Schoharie	518-295-8705
Schuyler	607-535-8140
Seneca	315-539-1920
St. Lawrence	315-386-2325
Steuben	607-664-2146
Suffolk	631-853-3100
Sullivan	845-292-0100 Ext. 2700
Tioga	607-687-8600
Tompkins	607-274-6644
Ulster	845-334-5251
Warren	518-761-6580
Washington	518-746-2400
Wayne	315-946-7262
Westchester	914-813-5094 or 813-5061
Wyoming	585-786-8850
Yates	315-536-5160

(Continued from previous page)

APPENDIX E: ADDITIONAL RESOURCES

The Arc of the United States (Association for Retarded Citizens) 1010 Wayne Avenue, Suite 650 Silver Spring, MD 20910	(800) 433-5255 (301) 565-3842 (301) 565-3843 (fax) www.thearc.org
The Association for Children With Down Syndrome 4 Fern Place Plainview, NY 11803	(516) 933-4700 (516) 933-9524 (fax) www.acds.org
Council for Exceptional Children 1110 North Globe Road Suite 300 Arlington, VA 22201	(888)-CEC-SPED (703) 620-3660 (703) 264-9494 (fax) www.cec.sped.org
Down Syndrome Parent Network 3226 Church Road Easton, PA 18045	(610) 432-3776 www.dspn.org
Easter Seals National Headquarters 230 West Monroe, Suite 1800 Chicago, IL 60606	(800) 221-6827 (312) 726-6200 www.easterseals.com
Educational Resources Information Center 4483-A Forbes Blvd. Lanham, MD 20706	(800)-538-3742 www.eric.ed.gov
International Foundation for Genetic Research 500A Garden City Drive Pittsburgh, PA 15146	(412) 823-6380 (412) 829-7304 (fax) www.michaelfund.org
March of Dimes Foundation 1275 Mamaroneck Avenue White Plains, NY 10605	(914) 428-7100 (914) 428-8203 (fax) www.modimes.org
National Down Syndrome Congress 1370 Center Drive, Suite 102 Atlanta, GA 30338	(800) 232-6372 (770) 604-9500 (770) 604-9898 (fax) www.ndsccenter.org
National Down Syndrome Society 666 Broadway, 8th Floor New York, NY 10012-2317	(800) 221-4602 (212) 460-9330 (212) 979-2873 (fax) www.ndss.org
National Information Center for Children and Youth with Disabilities (NICHCY) P.O. Box 1492 Washington, DC 20013-1492	(800) 695-0285 (202) 884-8200 (202) 884-8441 (fax) www.nichcy.org

Special Olympics International
13256 G Street, NW
Suite 500
Washington, DC 20005

(202) 628-3630
(202) 824-0200 (fax)
www.specialolympics.com

Note: *Inclusion of these organizations is not intended to imply an endorsement by the guideline panel or the NYSDOH. The guideline panel has not specifically reviewed the information provided by these organizations.*

Health Resources and Services Administration
U.S. Department of Health and Human Services
Parklawn Building
5600 Fishers Lane
Rockville, MD 20857

1-888-AskHRSA (275-4772)

www.ask.hrsa.gov
www.hrsa.gov/ConsumerEd/

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BIBLIOGRAPHY

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First author in **bold** indicates that the article met the criteria for evidence for this guideline.

1. Affleck, G. G., Tennen, H., Rowe, J., Roscher, B., and Walker, L. Effects of formal support on mothers' adaptation to the hospital-to-home transition of high-risk infants: The benefits and cost of helping. *Child Development* 1989; 60: 488-501.

2. Allen, D. B., Frasier, S. D., Foley, T. P., Jr., and Pescovitz, O. H. Growth hormone for children with Down syndrome. *Journal of Pediatrics* 1993; 123[5]: 742-743.

3. American Academy of Pediatrics, Committee on Genetics. Health supervision for children with Down syndrome. *Pediatrics* 1994; 93[5]: 855-859.

4. American Academy of Pediatrics. AAP issues guidelines on health supervision for children with Down syndrome. *American Family Physician* 1994; 50[3]: 695-697.

5. American Speech-Language-Hearing Association. Definition of communication disorders and variations. *ASHA* 1993; Supplement c10: 40-41.

6. Anneren, G., Gustafsson, J., Sara, V. R., and Tuvemo, T. Normalized growth velocity in children with Down's syndrome during growth hormone therapy. *Journal of Intellectual Disability Research* 1993; 37[Pt 4]: 381-387.

7. **Berry,** P. and Gunn, P. Maternal influence on the task behaviour of young Down's syndrome children. *Journal of Mental Deficiency Research* 1984; 28[4]: 269-274.

8. **Berry,** P., Gunn, P., and Andrews, R. J. The behaviour of Down's syndrome children using the 'Lock Box': A research note. *Journal of Child Psychology and Psychiatry* 1984A; 25[1]: 125-131.

9. **Bidder,** R. T., Bryant, G., and Gray, O. P. Benefits to Down's syndrome children through training their mothers. *Archives of Diseases in Childhood* 1975; 50: 383-386.

10. **Bidder,** R. T., Gray, P., Newcombe, R. G., Evans, B. K., and Hughes, M. The effects of multivitamins and minerals on children with Down syndrome. *Developmental Medicine and Child Neurology* 1989; 31[4]: 532-537.

11. Bigos, S., Bowyer, O., Braen, G., Brown, K., Deyo, R., Haldeman, S., Hart, J. L., Johnson, E. W., Keller, R., Kido, D., Liang, M. H., Nelson R. M., Nordin, M., Owen, B. D., Pope, M. H., Schwartz, R. K., Stewart, D. H., Susman, J., Triano, J. J., Tripp, L. C., Turk, D. C., Watts, C., and Weinstein, J. N. *Clinical Practice Guideline No. 14: Acute Low Back Problems in Adults.* Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, US Department of Health and Human Services, 1994. (AHCPR publication no. 95-0642).

12. **Bradley-Johnson,** S., Friedrich, D. D., and Wyrembelski, A. R. Exploratory behavior in Down's syndrome and normal infants. *Applied Research in Mental Retardation* 1981; 2[3]: 213-228.

13. **Bressanutti,** L., Sachs, J., and Mahoney, G. Predictors of young children's compliance to maternal behavior requests. *International Journal of Cognitive Education and Mediated Learning* 1992; 2[3]: 198-209.

14. **Bridges,** F. A. and Cicchetti, D. Mothers' ratings of the temperament characteristics of Down syndrome infants. *Developmental Psychology* 1982; 18[2]: 238-244.

15. **Bruder,** M. B. Parent-to-parent teaching. *American Journal of Mental Deficiency* 1987; 91[4]: 435-438.

16. Bruni, M, and Bruni, M. S. Fine Motor Skills in Children With Down Syndrome: A Guide for Parents and Professionals. Bethesda, MD: Woodbine House Publishing, 1998.

17. Bucci, I., Napolitano, G., Giuliani, C., Lio, S., Minnucci, A., Di Giacomo, F., Calabrese, G., Sabatino, G., Palka, G., and Monaco, F. Zinc sulfate supplementation improves thyroid function in hypozincemic Down children. *Biological Trace Element Research* 1999; 67[3]: 257-268.

18. **Carlstedt,** K., Dahllof, G., Nilsson, B., and Modeer, T. Effect of palatal plate therapy in children with Down syndrome: A 1-year study. *Acta Odontologia Scandinavica* 1996; 54[2]: 122-125.

19. **Carr,** J. Mental and motor development in young mongol children. *Journal of Mental Deficiency Research* 1970; 14: 205-220.

20. **Carvajal,** F. and Iglesias, J. Mother and infant smiling exchanges during face-to-face interaction in infants with and without Down syndrome. *Developmental Psychobiology* 1997; 31[4]: 277-286.

21. **Caselli,** M. C., Vicari, S., Longobardi, E., Lami, L., Pizzoli, C., and Stella, G. Gestures and words in early development of children with Down syndrome. *Journal of Speech, Language and Hearing Research* 1998; 41[5]: 1125-1135.

22. **Castells**, S., Beaulieu, I., Torrado, C., Wisniewski, K. E., Zarny, S., and Gelato, M. C. Hypothalamic versus pituitary dysfunction in Down's syndrome as cause of growth retardation. *Journal of Intellectual Disability Research* 1996; 40 [6]: 509-517.

23. Castiglia, P. T. Trisomy 21 syndrome: Is there anything new? *Journal of Pediatric Health Care* 1998; 12[1]: 35-37.

24. Centers for Disease Control and Prevention. National Center for Health Statistics. *National Health and Nutrition Examination Survey. Growth Charts*, 2000. http://www.cdc.gov/growthcharts

25. Chalmers, T. C., Smith, H. Jr., and Blackburn, B. A method for assessing the quality of a randomized control trial. *Controlled Clinical Trials* 1981, 2: 31-49.

26. Cicchetti, D. and Beeghly, M. An organizational approach to the study of Down syndrome: Contributions to an integrative theory of development. p. 29-62. In Children with Down Syndrome: A Developmental Perspective. Cicchetti, D. and Beeghly, M. (eds.). New York, NY: Cambridge University Press, 1990.

27. **Cielinski,** K. L., Vaughn, B. E., Seifer, R., and Contreras, J. Relations among sustained engagement during play, quality of play, and mother/child interaction in samples of children with Down syndrome and normally developing toddlers. *Infant Behavior and Development* 1995; 18 [2]: 163-176.

28. Clementi, M., Calzolari, E., Turolla, L., Volpato, S., and Tenconi, R. Neonatal growth patterns in a population of consecutively born Down syndrome children. *American Journal of Medical Genetics Suppl.* 1990; 7: 71-74.

29. **Cobo-Lewis,** A. B., Oller, D. K., Lynch, M. P., and Levine, S. L. Relations of motor and vocal milestones in typically developing infants and infants

with Down syndrome. *American Journal of Mental Retardation* 1996; 100[5]: 456-467.

30. Cohen, W. I. Down Syndrome Medical Interest Group: Health care guidelines for individuals with Down syndrome. *Down Syndrome Quarterly* 1996, 1[2].

31. Cohen, W. I. Health care guideline for individuals with Down syndrome: 1999 revision. *Down Syndrome Quarterly* 1999; 4[3]: 1-22.

32. **Coleman,** M., Sobel, S., Bhagavan, H. N., Coursin, D., Marquardt, A., Guay, M., and Hunt, C. A double blind study of vitamin B6 in Down's syndrome infants. Part 1— Clinical and biochemical results. *Journal of Mental Deficiency Research* 1985; 29[3]: 233-240.

33. Coleman, M. Vitamins and Down syndrome. *Down Syndrome Quarterly* 1997; 2[2]: 11-13.

34. **Connolly,** B. and Russell, F. Interdisciplinary early intervention program. *Physical Therapy* 1976; 56: 155-158.

35. **Connolly,** B., Morgan, S., Russell, F. F., and Richardson, B. Early intervention with Down syndrome children: Follow-up report. *Physical Therapy* 1980; 60[11]: 1405-1408.

36. **Connolly,** B. H., Morgan, S., and Russell, F. F. Evaluation of children with Down syndrome who participated in an early intervention program: Second follow-up study. *Physical Therapy* 1984; 64[10]: 1515-1519.

37. **Connolly,** B. H., Morgan, S. B., Russell, F. F., and Fulliton, W. L. A longitudinal study of children with Down syndrome who experienced early intervention programming. *Physical Therapy* 1993; 73[3]: 170-181.

38. Cooley, W. C. and Graham, J. M., Jr. Down syndrome: An update and review for the primary pediatrician. *Clinical Pediatrics* (Philadelphia) 1991; 30[4]: 233-253.

39. Cooley, W. C. Supporting the family of the newborn with Down syndrome. *Comprehensive Therapy* 1993; 19[3]: 111-115.

40. Courage, M. L., Adams, R. J., Reyno, S., and Kwa, P. G. Visual acuity in infants and children with Down syndrome. *Developmental Medicine and Child Neurology* 1994; 36[7]: 586-593.

41. Courage, M. L., Adams, R. J., and Hall, E. J. Contrast sensitivity in infants and children with Down syndrome. *Vision Research* 1997; 37[11]: 1545-1555.

42. Cronk, C., Crocker, A. C., Pueschel, S. M., Shea, A. M., Zackai, E., Pickens, G., and Reed, R. B. Growth charts for children with Down syndrome: 1 month to 18 years of age. *Pediatrics* 1988; 81[1]: 102-110.

43. **Crown,** C. L., Feldstein, S., Jasnow, M. D., Beebe, B., and Jaffe, J. Down's syndrome and infant gaze: Gaze behavior of Down's syndrome and nondelayed infants in interactions with their mothers. *Acta Paedopsychiatrica*. 1992; 55[1]: 51-55.

44. Cunningham, C. *Understanding Down Syndrome: An Introduction for Parents.* Cambridge, MA: Brookline Books, 1982.

45. Cunningham, C. *Understanding Down Syndrome: An Introduction for Parents.* Cambridge, MA: Brookline Books, 1996.

46. **Cutler,** A. T., Benezra-Obeiter, R., and Brink, S. J. Thyroid function in young children with Down syndrome. *American Journal of Diseases of Children* 1986; 140[5]: 479-483.

47. de la Cruz, F., and Gerald, P. (eds.) Trisomy 21 (Down Syndrome): Research Perspectives. Baltimore, MD: University Park Press, 1981.

48. Down, J. L. H. Observations of an ethnic classification of idiots. *Journal of Mental Science* 1867.

49. **Dunst,** C. J. Stage transitioning in the sensorimotor development of Down's syndrome infants. *Journal of Mental Deficiency Research* 1988; 32[5]: 405-410.

50. Dunst, C. J., Trivette, C. M., Jodry, W. Influences of social support on children with disabilities and their families. p. 499-522. In *The Effectiveness of Early Intervention.* Guralnick, M. (ed.). Baltimore, MD: Paul H. Brooks Publishing, 1997

51. Eddy, D. M., Hasselblad, V. Analyzing evidence by the confidence and profile method. In *Clinical Practice Guideline Development: Methodology Perspectives.* McCormick, K. A., Moore, S. R., and Siegel, R. A. (eds.) Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, US Department of Health and Human Services, 1994. (AHCPR Publication No. 95-0009)

52. Ershow, A. G. Growth in black and white children with Down syndrome. *American Journal of Mental Deficiency* 1986; 90[5]: 507-512.

53. Fort, P., Lifshitz, F., Bellisario, R., Davis, J., Lanes, R., Pugliese, M., Richman, R., Post, E. M., and David, R. Abnormalities of thyroid function in infants with Down syndrome. *Journal of Pediatrics* 1984; 104[4]: 545-549.

54. **Frager,** J., Barnet, A., Weiss, I., and Coleman, M. A double blind study of vitamin B6 in Down's syndrome infants. Part 2— Cortical auditory evoked potentials. *Journal of Mental Deficiency Research* 1985; 29[3]: 241-246.

55. Franco, F. and Wishart, J. G. Use of pointing and other gestures by young children with Down syndrome. *American Journal of Mental Retardation* 1995; 100[2]: 160-182.

56. Garwick, A. W., Patterson, J., Bennett, F. C., and Blum, R. W. Breaking the news: How families first learn about their child's chronic condition. *Archives of Pediatric and Adolescent Medicine* 1995; 149[9]: 991-997.

57. Gibson, D. and Harris, A. Aggregated early intervention effects for Down's syndrome persons: Patterning and longevity of benefits. *Journal of Mental Deficiency Research* 1988; 32[Pt 1]: 1-17.

58. **Girolametto,** L. E. Improving the social-conversational skills of developmentally delayed children: an intervention study. *Journal of Speech and Hearing Disorders* 1988; 53[2]: 156-167.

59. **Glenn,** S. M., Cunningham, C. C., and Joyce, P. F. A study of auditory preferences in nonhandicapped infants and infants with Down's syndrome. *Child Development* 1981; 52[4]: 1303-1307.

60. **Gunn,** P., Berry, P., and Andrews, R. J. Looking behavior of Down syndrome infants. *American Journal of Mental Deficiency* 1982; 87[3]: 344-347.

61. Gunn, P. and Berry, P. The temperament of Down's syndrome toddlers and their siblings. *Journal of Child Psychology and Psychiatry* 1985; 26[6]: 973-979.

62. Guralnick, M. J. The effectiveness of early intervention for children with cognitive and general developmental delays. In *The Effectiveness of Early Intervention for At-Risk and Handicapped Children.* Guralnick, M. J. (ed.). New York, NY: Academic Press, 1987

63. Guralnick, M. J. Second-generation research in the field of early intervention. In *The Effectiveness of Early Intervention*. Guralnick, M.(ed.). Baltimore, MD: Paul H. Brooks Publishers, 1997.

64. **Haley,** S. M. Postural reactions in infants with Down syndrome: Relationship to motor milestone development and age. *Physical Therapy* 1986; 66[1]: 17-22.

65. **Haley,** S. M. Sequence of development of postural reactions by infants with Down syndrome. *Developmental Medicine and Child Neurology* 1987; 29[5]: 674-679.

66. **Harris,** S. R. Effects of neurodevelopmental therapy on motor performance of infants with Down's syndrome. *Developmental Medicine and Child Neurology* 1981; 23[4]: 477-483.

67. **Harris,** S. R. Physical therapy and infants with Down's syndrome: The effects of early intervention. *Rehabilitation Literature* 1981A; 42[11-12]: 339-343.

68. **Harris,** J. What does mean length of utterance mean? Evidence from a comparative study of normal and Down's syndrome children. *British Journal of Disorders of Communication* 1983; 18[3]: 153-169.

69. Hauser-Cram, P., Warfield, M. E. Shonkoff, J. P., Krauss, M. W., Upshur, C. C., and Sayer, A. Family influences on adaptive development in young children with Down syndrome. *Child Development* 1999; 70[4]: 979-989.

70. Hines, S. and Bennett, F. Effectiveness of early intervention for children with Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews* 1996; 2: 96-101.

71. Hodapp, R. M. and Zigler, E. F. Applying the developmental perspective to individuals with Down syndrome. p. 1-28. In Children with Down Syndrome: A Developmental Perspective. Cicchetti, D. and Beeghly, M. (eds.). New York, NY: Cambridge University Press, 1990.

72. Hohoff, A. and Ehmer, U. Effects of the Castillo-Morales stimulating plate on speech development of children with Down's syndrome: A retrospective study. *Journal of Orofacial Orthopedics* 1997; 58[6]: 330-339.

73. Holland, J. P. Development of a clinical practice guideline for acute low back pain. *Current Opinion in Orthopedics* 1995, 6: 63-69.

74. Holmes, L. B. Concern about Piracetam treatment for children with Down syndrome. *Pediatrics* 1999; 103[5 Pt 1]: 1078-1079.

75. **Huntington,** G. S. and Simeonsson, R. J. Down's syndrome and toddler temperament. *Child: Care, Health and Development* 1987; 13[1]: 1-11.

76. Institute of Medicine, Committee on Clinical Practice *Guidelines. Guidelines for Clinical Practice Guidelines: From Development to Use*. Field, M.J. and Lohr, K. N. (eds.) Washington, DC: National Academy Press, 1992.

77. **Jago,** J. L., Jago, A. G., and Hart, M. An evaluation of the total communication approach for teaching language skills to developmentally delayed preschool children. *Education and Training of the Mentally Retarded* 1984; 19[3]: 175-182.

78. **Kasari,** C., Mundy, P., Yirmiya, N., and Sigman, M. Affect and attention in children with Down syndrome. *American Journal of Mental Retardation* 1990; 95[1]: 55-67.

79. **Kasari,** C., Freeman, S., Mundy, P., and Sigman, M. D. Attention regulation by children with Down syndrome: Coordinated joint attention and social referencing looks. *American Journal of Mental Retardation* 1995; 100[2]: 128-136.

80. Kennedy, R. L., Jones, T. H., and Cuckle, H. S. Down's syndrome and the thyroid. *Clinical Endocrinology (Oxford)* 1992; 37[6]: 471-476.

81. **Knieps,** L. J., Walden, T. A., and Baxter, A. Affective expressions of toddlers with and without Down syndrome in a social referencing context. *American Journal of Mental Retardation* 1994; 99[3]: 301-312.

82. Knussen, C., and Sloper, P. Stress in families of children with disability: A review of risk and resistance factors. *Rehabilitation Literature* 1992; 1: 241-256.

83. Koch, R., and de la Cruz, F. (eds.) Down Syndrome (Mongolism): Research, Prevention, and Management. New York, NY: Brunner & Mazel Publishers, 1975.

84. **Krakow,** J. B. and Kopp, C. B. The effects of developmental delay on sustained attention in young children. *Child Development* 1983; 54[5]: 1143-1155.

85. Krauss, M. W. Two generations of family research in early intervention. p. 611-623. In *The Effectiveness of Early Intervention*. Guralnick, M. (ed.). Baltimore, MD: Paul H. Brooks Publishing, 1997.

86. Krilov, L. R., Barone, S. R., Mandel, F. S., Cusack, T. M., Gaber, D. J., and Rubino, J. R. Impact of an infection control program in a specialized preschool. *American Journal of Infection Control* 1996; 24[3]: 167-173.

87. Kumin, L. Communication Skills in Children With Down Syndrome: A Guide for Parents. Bethesda, MD: Woodbine House Publishing, 1994.

88. **Kysela,** G., Hillyard, A., McDonald, L., and Ahlsten-Taylor, J. Early intervention: Design and evaluation. p. 341-388. In *Language Intervention Series: Vol.6, Early Language: Acquisition and intervention*. Schiefelbusch, R. L. and Bricker, D. D. (eds.). Baltimore, MD: University Park Press, 1981.

89. **Landry,** S. H. and Chapieski, M. L. Joint attention and infant toy exploration: Effects of Down syndrome and prematurity. *Child Development* 1989; 60[1]: 103-118.

90. **Landry,** S. H. and Chapieski, M. L. Joint attention of six-month-old Down syndrome and preterm infants: I. Attention to toys and mother. *American Journal of Mental Retardation* 1990; 94[5]: 488-498.

91. **Landry,** S. H., Garner, P. W., Pirie, D., and Swank, P. R. Effects of social context and mothers' requesting strategies on Down's syndrome children's social responsiveness. *Developmental Psychology* 1994; 30[2]: 293-302.

92. Landsman, G. H. Reconstructing motherhood in the age of "perfect" babies: Mothers of infants and toddlers with disabilities. *Signs: Journal of Women in Culture and Society* 1998; 24[1]: 69-99.

93. Landsman, G. H. Does God give special kids to special parents? Personhood and the child with disability as gift and as giver. p. 133-165. In Transformative Mothering: *On Giving and Getting in a Consumer Culture*. Layne, L. (ed.). New York, NY: New York University Press, 1999.

94. Landsman, G. H. "Real" motherhood: Class and children with disabilities. In *Technologies and Ideologies of Motherhood*. Ragone, H., and Winddance-Twine, F. (ed.). New York, NY: Routledge, Inc., 2000.

95. **Lewis,** V. A. and Bryant, P. E. Touch and vision in normal and Down's syndrome babies. *Perception* 1982; 11[6]: 691-701.

96. Lockitch, G., Puterman, M., Godolphin, W., Sheps, S., Tingle, A. J., and Quigley, G. Infection and immunity in Down syndrome: A trial of long-term low oral doses of zinc. *Journal of Pediatrics* 1989; 114[5]: 781-787.

97. **Loveland,** K. A. Behavior of young children with Down syndrome before the mirror: Exploration. *Child Development* 1987; 58[3]: 768-778.

98. **Loveland,** K. A. Behavior of young children with Down syndrome before the mirror: Finding things reflected. *Child Development* 1987A; 58[4]: 928-936.

99. **Lydic,** J. S., Windsor, M. M., Short, M. A., and Ellis, T. A. Effects of controlled rotary vestibular stimulation on the motor performance of infants with Down's syndrome. *Physical and Occupational Therapy in Pediatrics* 1985; 5[2/3]: 93-118.

100. **Lynch,** M. P., Oller, D. K., Steffens, M. L., Levine, S. L., Basinger, D. L., and Umbel, V. Onset of speech-like vocalizations in infants with Down syndrome. *American Journal of Mental Retardation* 1995; 100[1]: 68-86.

101. **MacTurk,** R. H., Vietze, P. M., McCarthy, M. E., McQuiston, S., and Yarrow, L. J. The organization of exploratory behavior in Down syndrome and nondelayed infants. *Child Development* 1985; 56[3]: 573-581.

102. Magnusson, C. G., Nordvall, S. L., and Anneren, G. Differential effect of selenium supplementation on immunoglobulin levels in Down's syndrome. *Acta Paediatrica* 1997; 86[12]: 1385-1386.

103. **Mahoney,** G., Glover, A., and Finger, I. Relationship between language and sensorimotor development of Down syndrome and nonretarded children. *American Journal of Mental Deficiency* 1981; 86[1]: 21-27.

104. **Mahoney,** G., Fors, S., and Wood, S. Maternal directive behavior revisited. *American Journal of Mental Retardation* 1990; 94[4]: 398-406.

105. **Marcovitch,** S., Goldberg, S., MacGregor, D. L., and Lojkasek, M. Patterns of temperament variation in three groups of developmentally delayed preschool children: Mother and father ratings. *Journal of Developmental and Behavioral Pediatrics* 1986; 7[4]: 247-252.

106. **Marcovitch,** S., Goldberg, S., Lojkasek, M., and MacGregor, D. L. The concept of difficult temperament in the developmentally disabled preschool child. *Journal of Applied Developmental Psychology* 1987; 8[2]: 151-164.

107. McCollum, J. A., Hemmeter, M. L. Parent-child interaction intervention when children have disabilities. In *The Effectiveness of Early Intervention*. Guralnick, M. (ed.). Baltimore, MD: Paul H. Brooks Publishers, 1997.

108. Meyerson, M. D. The effect of syndrome diagnosis on speech remediation. Birth Defects Original Article Series 1985; 21[2]: 47-68.

109. **Mundy,** P., Sigman, M., Kasari, C., and Yirmiya, N. Nonverbal communication skills in Down syndrome children. *Child Development* 1988; 59[1]: 235-249.

110. New York State Department of Health, Early Intervention Program. *Autism/ Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3 Years).* Albany, NY: New York State Department of Health, 1999. Publication No. 4215.

111. New York State Department of Health, Early Intervention Program. *Communication Disorders: Assessment and Intervention for Young Children (Age 0-3 Years).* Albany, NY: New York State Department of Health, 1999. Publication No. 4218.

112. Nickel, R. E. Controversial therapies for young children with developmental disabilities. *Infants and Young Children* 1996; 8[4]: 29-40.

113. **Ohr,** P. S. and Fagen, J. W. Conditioning and long-term memory in three-month-old infants with Down syndrome. *American Journal of Mental Retardation* 1991; 96[2]: 151-162.

114. **Ohr,** Phyllis S. and Fagen, Jeffrey W. Temperament, conditioning, and memory in 3-month-old infants with Down syndrome. *Journal of Applied Developmental Psychology* 1993; 14[2]: 175-190.

115. Palmer, C. G., Cronk, C., Pueschel, S. M., Wisniewski, K. E., Laxova, R., Crocker, A. C., and Pauli, R. M. Head circumference of children with Down syndrome (0-36 months). *American Journal of Medical Genetics* 1992; 42[1]: 61-67.

116. Palmer, F. B. and Capute, A. J. Mental retardation. Pediatrics in Review 1994; 15[12]: 473-479.

117. Pappas, D. G., Flexer, C., and Shackelford, L. Otological and habilitative management of children with Down syndrome. *Laryngoscope* 1994; 104[9]: 1065-1070.

118. Patterson, J., et al. Social support in families of children with chronic conditions: Supportive and nonsupportive behaviors. *Developmental and Behavioral Pediatrics* 1997; 18[6]: 383-389.

119. **Piper,** M. C. and Pless, I. B. Early intervention for infants with Down syndrome: A controlled trial. *Pediatrics* 1980; 65[3]: 463-468.

120. Pipes, P. L. and Holm, V. A. Feeding children with Down's syndrome. *Journal of the American Dietetic Association* 1980; 77[3]: 277-282.

121. **Poulson,** C. L. Operant conditioning of vocalization rate of infants with Down syndrome. *American Journal of Mental Retardation* 1988; 93[1]: 57-63.

122. Powe, N. R., Turner, J. A., Maklan, C. W., and Ersek, R. N. Alternative methods for formal literature review and meta-analysis in AHCPR patient outcomes research teams. *Medical Care* 1994, 32: 22-37.

123. Pruess, J. B., Fewell, R. R., and Bennett, F. C. Vitamin therapy and children with Down syndrome: A review of research. *Exceptional Children* 1989; 55[4]: 336-341.

124. Pueschel, S., and Rynders, J. (eds.) *Down Syndrome: Advances in Biomedicine and the Behavioral Sciences.* Cambridge, MA: The Ware Press, 1982.

125. Pueschel, S. M. Clinical aspects of Down syndrome from infancy to adulthood. *American Journal of Medical Genetics Suppl.* 1990; 7: 52-56.

126. Pueschel, S. M. The person with Down syndrome: Medical concerns and educational strategies. p. 53-60. In *Down Syndrome: Advances in Medical Care*. Lott, I. T. and McCoy, E. E. (eds.). New York, NY: John Wiley and Sons, 1992.

127. Pueschel, S. M., Anneren, G., Durlach, R., Flores, J., Sustrova, M., and Verma, I. C. Guidelines for optimal medical care of persons with Down syndrome. *Acta Paediatrica* 1995; 84[7]: 823-827.

128. **Purdy,** A. H., Deitz, J. C., and Harris, S. R. Efficacy of two treatment approaches to reduce tongue protrusion of children with Down syndrome. *Developmental Medicine and Child Neurology* 1987; 29[4]: 469-476.

129. **Rast,** M. M. and Harris, S. R. Motor control in infants with Down syndrome. *Developmental Medicine and Child Neurology* 1985; 27[5]: 682-685.

130. Reading, C. M. Down's syndrome: Nutritional intervention. Nutrition and Health 1984; 3[1-2]: 91-111.

131. Richard, N. B. Interaction between mothers and infants with Down syndrome: Infant characteristics. *Topics in Early Childhood Special Education* 1986; 6[3]: 54-71.

132. Roizen, N. J., Wolters, C., Nicol, T., and Blondis, T. A. Hearing loss in children with Down syndrome. *Journal of Pediatrics* 1993; 123[1]: S9-12.

133. Roizen, N. J., Martich, V., Ben Ami, T., Shalowitz, M. U., and Yousefzadeh, D. K. Sclerosis of the mastoid air cells as an indicator of undiagnosed otitis media in children with Down's syndrome. *Clinical Pediatrics (Philadelphia)* 1994; 33[7]: 439-443.

134. Roizen, N. J., Mets, M. B., and Blondis, T. A. Ophthalmic disorders in children with Down syndrome. *Developmental Medicine and Child Neurology* 1994; 36[7]: 594-600.

135. Roizen, N. J. New advancements in medical treatment of young children with Down syndrome: Implications for early intervention. *Infants and Young Children* 1997; 9[4]: 36-42.

136. Rosenberg, H. C., Jung, J. H., Soltan, H. C., Li, M. D., and Sheridan, G. Cardiac screening of children with Down's syndrome. *Canadian Journal of Cardiology* 1994; 10[6]: 675-677.

137. **Rothbart,** M. K. and Hanson, M. J. A caregiver report: Comparison of temperamental characteristics of Down syndrome and normal infants. *Developmental Psychology* 1983; 19[5]: 766-769.

138. **Ruskin,** E. M., Kasari, C., Mundy, P., and Sigman, M. Attention to people and toys during social and object mastery in children with Down syndrome. *American Journal of Mental Retardation* 1994; 99[1]: 103-111.

139. Rynders, J., Spiker, D., and Horrobin, J. Underestimating the educability of Down's syndrome children: Examination of methodological problems in recent literature. *American Journal of Mental Deficiency* 1978; 82: 440-448.

140. Rynders, J. E., Rand, Y., Feuerstein, R., and Klein, P. Early education for children with Down syndrome and their parents. p. 129-147. In Don't Accept Me as I Am: Helping "Retarded" People to Excel. Feuerstein, R., Rand, Y., and Rynders, J. E. (eds.). New York, NY: Plenum Press, 1988.

141. Sackett, D. L., Haynes, R. B., Guyatt, G. H., and Tugwell, P. *Clinical Epidemiology: A Basic Science for Clinical Medicine, 2nd edition.* Boston, MA: Little, Brown, 1991.

142. Saenz, R. B. Primary care of infants and young children with Down syndrome. *American Family Physician* 1999; 59[2]: 381-386.

143. Sanz, M. T. and Menendez, J. A Study of the effect of age of onset of treatment on the observed development of Down's syndrome babies. *Early Child Development and Care* 1996; 118: 93-101.

144. Scarr, S. Developmental theories for the 1990s: Development and individual differences. *Child Development* 1992; 63: 1-19.

145. **Schoen,** S. F., et al. An examination of two prompt fading procedures and opportunities to observe in teaching handicapped preschoolers self-help skills. *Journal of the Division for Early Childhood* 1988; 12[4]: 349-358.

146. Schriger, D.L. Training panels in methodology. In *Clinical Practice Guideline Development: Methodology Perspectives.* McCormick, K. A., Moore, S. R., and Siegel, R. A. (eds.) Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, US Department of Health and Human Services, 1994. (AHCPR Publication No. 95-0009)

147. Selikowitz, M. Short-term efficacy of tympanostomy tubes for secretory otitis media in children with Down syndrome. *Developmental Medicine and Child Neurology* 1993; 35[6]: 511-515.

148. Serra, A. and Neri, G. Trisomy 21: Conference report and 1990 update. *American Journal of Medical Genetics Suppl.* 1990; 7: 11-19.

149. Sharav, T., Landau, H., Zadik, Z., and Einarson, T. R. Age-related patterns of thyroid-stimulating hormone response to thyrotropin-releasing hormone stimulation in Down syndrome. *American Journal of Diseases of Children* 1991; 145[2]: 172-175.

150. Shaughnessy, J. J., and Zechmeister, E. B. Single case research designs. p. 305-335. In *Research Methods in Psychology, 4th edition.* New York, NY: McGraw Hill, 1997.

151. Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., and Upshur, C. C. Development of infants with disabilities and their families: Implications for theory and service delivery. *Monographs of the Society for Research in Child Development* 1992; 57[6]: 1-153.

152. **Sloper,** P., Glenn, S. M., and Cunningham, C. C. The effect of intensity of training on sensori-motor development in infants with Down's syndrome. *Journal of Mental Deficiency Research* 1986; 30 [2]: 149-162.

153. Smith, G., and Berg, J. Down's Anomaly. London: Churchill Livingstone Press, 1976.

154. Spiker, D. Early intervention from a developmental perspective. In *Children with Down Syndrome*. Cicchetti, D. and Beeghly, M. (ed.). Cambridge, MA: Cambridge University Press, 1990.

155. Spiker, D. and Hopmann, M. R. *The Effectiveness of Early Intervention* for children with Down syndrome. p. 271-305. *The Effectiveness of Early Intervention*. Guralnick, M. Baltimore, MD: Paul H. Brookes Publishing Co., 1997.

156. **Steffens,** M. L., Oller, D. K., Lynch, M., and Urbano, R. C. Vocal development in infants with Down syndrome and infants who are developing normally. *American Journal of Mental Retardation* 1992; 97[2]: 235-246.

157. Stray-Gundersen, K. Babies with Down Syndrome: A New Parents' Guide, 2nd edition. Bethesda, MD: Woodbine House Publishing, 1995.

158. **Tannock,** R. Mothers' directiveness in their interactions with their children with and without Down syndrome. *American Journal of Mental Retardation* 1988; 93[2]: 154-165.

159. Tingey, C. Down Syndrome: A Resource Handbook. Boston, MA: College Hill Press, 1988.

160. Tolmie, J. L. Down syndrome and other autosomal trisomies. *Principles and Practice of Medical Genetics* 1998; 47: 925-971.

161. Torfs, C. P. and Christianson, R. E. Anomalies in Down syndrome individuals in a large population-based registry. *American Journal of Medical Genetics* 1998; 77[5]: 431-438.

162. Torrado, C., Bastian, W., Wisniewski, K. E., and Castells, S. Treatment of children with Down syndrome and growth retardation with recombinant human growth hormone. *Journal of Pediatrics* 1991; 119[3]: 478-483.

163. Tubman, T. R., Shields, M. D., Craig, B. G., Mulholland, H. C., and Nevin, N. C. Congenital heart disease in Down's syndrome: two year prospective early screening study. *BMJ* 1991; 302[6790]: 1425-1427.

164. **Ulrich,** B. D. and Ulrich, D. A. Spontaneous leg movements of infants with Down syndrome and nondisabled infants. *Child Development* 1995; 66[6]: 1844-1855.

165. **Ulrich,** B. D., Ulrich, D. A., Angulo-Kinzler, R., and Chapman, D. D. Sensitivity of infants with and without Down syndrome to intrinsic dynamics. *Research Quarterly for Exercise and Sport* 1997; 68[1]: 10-19.

166. Van Dyke, D. C., Lang, D. J., van Duyne, S., Heide, F., and Chang, H. J. Cell therapy in children with Down syndrome: A retrospective study. *Pediatrics* 1990; 85[1]: 79-84.

167. **Vaughn,** B. E., Contreras, J., and Seifer, R. Short-term longitudinal study of maternal ratings of temperament in samples of children with Down syndrome and children who are developing normally. *American Journal of Mental Retardation* 1994; 98[5]: 607-618.

168. Vaughn, B. E., Goldberg, S., Atkinson, L., Marcovitch, S., MacGregor, D., and Seifer, R. Quality of toddler-mother attachment in children with Down syndrome: Limits to interpretation of strange situation behavior. *Child Development* 1994A; 65[1]: 95-108.

169. Wang, P. P. and Bellugi, U. Williams syndrome, Down syndrome, and cognitive neuroscience. *American Journal of Diseases of Children* 1993; 147[11]: 1246-1251.

170. Warfield, M. E., Krauss, M. W., Hauser-Cram, P., and Shonkoff, J. P. Adaptation during early childhood among mothers of children with disabilities. *Journal of Developmental and Behavioral Pediatrics* 1999; 20[1]: 9-16.

171. Website: Canadian Down Syndrome Society: http://www.cdss.ca/library.html

172. Website: National Association for Down Syndrome: http://www.nads.org/

173. Website: National Down Syndrome Congress: http://ndsccenter.org

174. Website: National Down Syndrome Society: http://www.ndss.org

175. Werner, D. Mental retardation: Down syndrome, cretinism, and other causes, p. 277-282. In disabled Village Children. Werner, D. (ed.) Palo Alto, CA: Hesperian Foundation, 1987.

176. Werner, L.A., Manol, L.R. and Folsom, R.C. Preliminary observations on the development of auditory sensitivity in infants with Down syndrome. *Ear and Hearing* 1996; 17[6]: 455-468.

177. Winders, P.C. Gross Motor Skills in Children With Down Syndrome: A Guide for Parents and Professionals. Bethesda, MD: Woodbine House Publishing, 1997.

178. **Wishart,** J.G. Performance of young nonretarded children and children with Down syndrome on Piagetian infant search tasks. *American Journal of Mental Deficiency* 1987; 92[2]: 169-177.

179. Wolery, M. Using assessment information to plan instructional programs, p. 478-495. In *Assessing Infants and Preschoolers with Handicaps*. Columbus, OH" Charles E. Merrill, 1989.

180. Woodhouse, J.M., Pakeman, V.H., Saunders, .J., Parker, M., Fraser, W.I., Lobo, S., and Sastry, P. Visual acuity and accommodation in infants and young children with Down syndrome. *Journal of Intellectual Disability Research* 1996; 40[Pt 1]: 49-55.

181. Woodhouse, J.M., Pakeman, V.H., Cregg, M., Saunders, .J., Parker, M., Fraser, W.I., Sastry, P., and Lobo, S. Refractive errors in young children with Down syndrome. *Optometry and Vision Science* 1997; 74[10]: 844-951.

182. Woodhouse, J.M., Investigating and managing the child with special needs. Opthalmic and Physiological Optics 1998; 18[2]: 147-152.

183. Woolf, S.H. *AHCPR Interim Manual for Clinical Practice Guideline Development*. Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, US Department of Health and Human Services, 1991, (AHCPR Publication No. 91-0018)

184. Woolf, S.H. An organized analytic framework for practice guideline development: Using the analytic logic as a guide for reviewing evidence, developing recommendations, and explaining the rationale. In *Clinical Practice Guideline Development: Methodology Perspectives*. McCormick, K.A., Moore, S.R. and Siegel, R.A. (eds.) Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, US Department of Health and Human Services, 1994. (AHCPR Publication No. 95-0009)

185. Wren, C., Richmond, S., and Donaldson, L. Presentation of congenital heart disease in infants: Implications for routine examination. *Archives of Diseases in Childhood Fetal Neonatal Edition* 1999; 80[1]: F49-F53.

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